

Using *On Our Own Terms* for Discussion and Community Outreach

by Mari Cossaboom
and Megan Scribner

Using the Guide

This Discussion Guide provides background material on each program and offers practical information about end-of-life care. Facilitators should distribute the guide to discussion-group participants before viewing the program. If you don't have enough copies for everyone, photocopy the guide or download it from the Web site. Look to "Issues for Further Consideration" for suggested discussion questions for each of the programs. Also, refer to the *On Our Own Terms* Leadership Guide published in September 1999 to find ideas for taking community action. The Leadership Guide is also available for downloading on the *On Our Own Terms* Web site. These resources can help you effectively use *On Our Own Terms* as a catalyst for dialogue and community action.

Woody Allen once said, "It's not that I'm afraid to die. I just don't want to be there when it happens." We all know that we'll die eventually, but many of us prefer to avoid discussing it and making plans for it. While the subject may make us uncomfortable, there are good reasons for talking about the topic. One important reason is to ensure that we get the kind of end-of-life care we want for our family members, our community, and ourselves.

On Our Own Terms: Moyers on Dying can inspire these end-of-life discussions. You can use the four programs in *On Our Own Terms*, this Discussion Guide, and the Web site as resources for talking about death and dying with your family. The Discussion Guide includes a number of practical suggestions for discussion topics and lists resources for learning more about your options. You can use any of the following components informally with family and friends, or in organized discussion groups that may take place in workplaces, community-based organizations, educational settings, and congregations:

- *On Our Own Terms* (the four-part series)
- This Discussion Guide
- The *On Our Own Terms* Web site (www.thirteen.org/onourown/terms)

Talking with Your Family

It can be difficult to begin talking about death and dying with your family. It can seem emotional, sad, and frightening. Yet, talking can help provide peace of mind; it is an opportunity for everyone to learn about the needs and wishes of their loved ones. It may be easier to think of it as an opportunity to share, not how we want to die, but how we want to live.

It's best to talk about end-of-life issues before a crisis occurs. When there is an emergency and people feel pushed to make decisions, those involved may feel too anxious or preoccupied to talk about what is going on. Discussing these issues ahead of time can give you the strength and commitment to be an advocate for your loved one.

Key topics for families to discuss include:

- When would you want medical treatment to offer comfort rather than prolong life?
 - Who would you want to make your healthcare decisions if you could not speak for yourself?
 - What are your religious, cultural, or philosophical beliefs about death and dying?
 - How do you want to live at the end of your life?
- (See "How to Talk about End-of-Life Concerns," page 14)

Themes for Planning Discussions

Program 1, "Living with Dying"—Segment(s) that portray experiences of living with death can inspire dialogue on how the dying can find meaning in the experience if it is faced honestly and as an inevitable and inherent part of life.

Program 2, "A Different Kind of Care"—Segment(s) demonstrating palliative care can frame a discussion with medical or nursing students and/or healthcare professionals that help them put these important principles into practice.

Using the Series with Discussion Groups

Viewing carefully selected video segments from *On Our Own Terms* can be an effective means to introduce a sensitive subject. The series presents personal stories of dying people, their families, and the complex choices that we all must face. These accounts can encourage group members to discuss how they might manage in similar situations, and to explore their own fears and concerns about dying. Once viewers understand their personal feelings, they are better prepared to talk with their families and healthcare providers.

Small Groups

If you are experienced with facilitating discussions, you can use the series, guide, and Web site in small groups such as study circles, brown bag lunches at work, or in adult-education settings.

Some may feel that death is too personal and emotionally charged to talk about in a small group. For others, exploring fears and perspectives of death in a small group can be less traumatic than in a family setting and can create ideas and openings for discussions with family members and close friends.

If you organize this kind of discussion, be aware that people will differ in their degree of openness, and each person must feel free to participate at his or her own comfort level. A range of emotions may emerge—fear, anger, grief, confusion, joy, empathy, and compassion—all of which can offer insights.

If participants in your group don't know each other well, you might begin by asking what would help them openly express their feelings and ideas. Invite them to say what brought them to the group and to share their own stories. For some, pausing for a moment of silence or lighting a candle may create a more reflective mood. For others, beginning with a brief story or a poem can help.

Conversations on death and dying may trigger intense feelings. Some may avoid these feelings by trying to trivialize or divert the conversation. Others may experience intense emotions that could overwhelm the group. At these times, it is helpful for the facilitator to acknowledge a person's pain and gently refocus the conversation.

Log On! The *On Our Own Terms* Web site at www.pbs.org/onourownterms or www.thirteen.org/onourownterms offers ways to get involved in these issues now. In the fall it will expand to offer articles, stories and descriptions of local initiatives that can help you get involved in your community.

The following questions may be related to stories from the series and the guide, and are helpful for focusing small-group discussion:

- Has anyone close to you died? What did the experience teach you? If it was a prolonged death, did they change during the process? Did you? If so, how?
- What do you hope your death will be like? What do you imagine it will be like?
- How do your beliefs influence your perspective on dying? Do you believe that there are any positive aspects of the dying process for the dying person or for his or her loved ones?
- What might make the idea of dying more bearable for you? Have you talked with your loved ones about what all of your wishes might be?
- What thoughts or feelings do you have concerning what, if anything, might come after death?
- What or who has influenced your thinking?

Larger Groups

On Our Own Terms can also be used in educational settings, congregations, town-hall meetings, or public forums to stimulate discussion of larger community issues.

There are several techniques for using the video effectively to stimulate conversation:

- Select a topic for discussion that meets the objective for the group. Preview the program to identify brief segments that clearly illustrate the chosen topic. Brief, carefully selected segments are often most effective.
- Introduce the program and topic prior to viewing the segment(s) with the group. Provide a focus for viewing by asking participants to listen for key concepts, consider specific issues, or take note of their own reactions to the content as they watch the video.
- After viewing the segment(s), give the participants time to react to what they saw. Refer them back to the specific focus and elicit their responses. Help them relate the content of the video to their own experiences.
- Find reading materials that underscore the themes of the video segments: selected poems, book excerpts, or news articles. Try role-playing activities or writing exercises.

Program 3, “A Death of One’s Own”—Segment(s) that illustrate the dilemmas facing the dying and their families can initiate a dialogue on how to exercise greater choice and control at the end, so that the wishes of the individual are honored in the most difficult of circumstances.

Program 4, “A Time to Change”—Segment(s) that feature successful community models can motivate town-meeting participants to consider how local communities, hospitals, hospices, nursing homes, and religious and other institutions can respond to the needs of the dying and their families.

Program 1

Certificate of Attendance

“On Our Own Terms” Moyers on Dying

This is to certify that _____
has completed the following inservice or self-study video and learning packet designed
with the continuing education standards of the Minnesota Board of Nursing in mind. It is
the responsibility of each professional to determine if this meets his or her relicensure
requirements.

Program Title: Program 1: Living with Dying

Presenter:

Name of Program Facilitator, Degree License

Title of Program Facilitator

Name of Sponsoring Organization

Date:

Time: Two contact hours

Location:

Name of Sponsoring Organization

Address

City, State, Zip

Signature of Program Facilitator

Date

Living with Dying

“Living with Dying” explores America’s search for new ways of thinking about dying and constructive ways to talk about it with one another. It focuses on people—patients and caregivers—who are finding ways to overcome the fear and denial that dominate mainstream American culture and open conversations that help us live with dying.

Grandmother’s Garden by Myra J. Christopher

On Mother’s Day, 1978, when we visited Mom in the hospital, she told us she believed the multiple rounds of chemotherapy, radiation, ICU stays, and surgeries, including this last one, had been worth it because they had bought her some time. “But now, it’s time to go home and ‘take care of business,’” she said.

I knew Mom was dying. Immediately after surgery, the doctor had told us that she couldn’t possibly live six more months.

However, at that point, I had no idea what the “business” of dying would be.

Mom had lived with my husband, Truman, our two daughters, and me since my father’s death in 1972. I was glad she wanted to die at home, so that our daughters, then six and ten, could share this precious time with the woman who had been the most important person in my life.

Shortly after coming home, Mom announced that she planned to piece a quilt. She had always done handwork—crochet, cross-stitch, and embroidery—but I had never known her to quilt. When I asked why, she said, “Dying is boring, and it’s never too late to learn something new.” The idleness associated with incapacity was maddening to her.

Over the next few months, Mom worked diligently on the quilt, a simple pattern called “Grandmother’s Garden” that radiates outward from a single octagon. Little could I have imagined the importance of Mom’s quilt.

As she picked up a piece of calico, she would say, “...This reminds me of the dress you wore your first day of school,” or “This blue was your father’s favorite color.” Each recollection opened the door for a conversation about those things that she wanted to share.

As the quilt grew, Mom weakened. It was a poignant reminder that time was passing too quickly. At last, she became too sick to work on the quilt. I teased her, saying, “You better hurry; you know I want it to be king-size.”

Mom died before the quilt was finished, but it was all right. She had creatively used it as a tool to teach me her final lesson, that the “business” of dying is something best done at home, not in an intensive-care unit. This is because the real “business” of dying is reaffirming relationships that have given one’s life meaning.

Without my knowledge, two Christmases later, my husband’s parents finished the quilt for me. It was the most wonderful gift imaginable.

Mom’s quilt has served our family in many ways she would have liked—picnic-cloth, moving-pad, bedspread, and wrap for her great-grandson. Each time, the quilt reminds me of the bond between generations and the important “business” of dying.



Photo © Donna Beckward

Holding grandmother’s quilt

The Rise of Medical Technology

One hundred years ago, the average age of death in America was 46. Most people died at home, usually as the result of a disease or accident. Due to advances in medicine and technology, the average life expectancy in the U.S. has increased by more than 30 years, and the setting in which most Americans die has changed. Eighty percent of us die in hospitals and other healthcare institutions. Public opinion surveys show that most Americans would prefer to die at home, and do not want to die in pain, dependent on machines in an impersonal institution. The interest in alternatives has spurred the growth of hospice and palliative care. (See Glossary for definitions)

A Healthcare Professional's Concerns by Gerald Jonas

Caregiving for the dying can often help professional caregivers learn more about their patients and their profession. Dr. Pat Caralis sees her job as helping people take control of their dying. She believes that the first step is good communication. For professional caregivers in hospitals and other institutions, she says, the process begins with listening carefully to patients and their families who often face agonizing choices they may not fully understand.

Dr. Caralis's insights into the American way of dying come from experience. She is Chief of General Medicine at Miami's VA Medical Center and head of Jackson Memorial Hospital's bioethics committee, and she knows the challenge of caring for individual patients as well as the complexities of making policy for a large medical institution.

She has learned how hard it is for most Americans to talk about death. "As a culture," she notes, "we lack first-hand knowledge of dying. A hundred years ago people growing up probably saw someone close to them die at home. But over the last century we have institutionalized death, so that most people now die in a hospital or nursing home."

Institutions like hospitals often focus on prolonging life and may consider death a "defeat." High-tech interventions (like breathing and feeding tubes) have become commonplace. In many cases, healthcare professionals, and not patients' families, make the crucial life-and-death decisions.

Dr. Caralis would like to see society adopt a more balanced view of dying, as represented by hospice and palliative care. These types of care focus on pain relief and improving the dying person's experience. They are available in some hospitals and stand-alone institutions, but they are most common at home, where medical and other professionals oversee the care given by the family.

Conversations between healthcare professionals and patients and their families are often made more difficult by differences in

language, culture, and religion. Sometimes families feel that the experience of pain is necessary to spur a patient's struggle to recover or that stopping curative or life-sustaining efforts is tantamount to doing nothing for the patient. Treatment might be continued or stopped based on the religious idea that God is the only one who can decide that it is time to die.

Sometimes cultural differences can dictate behavior. According to research done by Dr. Caralis, African-Americans are most likely to request that life-sustaining interventions be continued, perhaps to compensate for inadequate medical care in the past. Latinos may be hesitant to pass along a grim prognosis to patients, in the belief that sharing the news may hurt the patient's chances of recovery. Some cultures never speak words like "cancer" aloud.

In helping patients and families, compassionate caregivers must take into account people's beliefs and how they receive and react to information. Healthcare professionals should work with experts from other fields, like clergy, if they can help the medical team and family communicate better. Dr. Caralis cites a recent case in which devoutly religious family members resisted talking to a physician about the futility of continuing life support for a dying relative because of their belief in miracles. Yet they had no trouble accepting the inevitable after speaking with a clergyman on the hospital's complementary-care team.

"I don't know about the rest of you, but I cannot live each day as if it is the last day that I am going to be alive. I can't. That makes life really hard for me. But what I did discover is that I can live by the calendar method; I can live in yearlong segments. I could live each day on the calendar as if it were the last time I would be above ground on that day. I could live each birthday that way, each wedding anniversary, each spring, each Christmas. And it not only worked, it actually made each of those days more special than it would otherwise have been."

Bill Bartholome (1944–1999), from Meditations



A Century of Change: 1900 2000

	1900	2000
Age at death	46 years	78 years
Leading causes	Infection Accident Childbirth	Cancer Heart Disease Stroke/Dementia
Disability before death	Unusual and brief	On average, more than 4 years
Costs	Low, affordable	Very costly, for long periods
Financing	Mostly private, from family	Mostly Medicare and Medicaid

(adapted from *Handbook for Mortals*, Lynn and Harrold, 1999)

“Those who bring sunshine to others cannot keep it from themselves.”

—Sir James Barrie

How to Be with a Dying Person by the Rev. Chuck Meyer

There are no “right” things friends or other family members can do for the patient and family. But there are things anyone can offer before, during, and after the patient has died.

BEFORE: Be there. Check in with the person and family periodically—daily or weekly. From the instant of initial diagnosis, some friends, family, and loved ones may start to distance themselves, on the false assumption that disconnecting now will mean less hurt later.

Listen more than talk—Follow the patient’s need for conversation, whether about family, weather, politics, spiritual issues, or dying (though it is *not required* to talk of dying.) Serve as a resource to the patient to get those issues addressed.

Death planning—At the appropriate time, sensitively ask whether the patient has advance directives (living will, medical power of attorney), has fears about end-of-life care that you can help calm, or wishes about where to die (home or hospital), including preferences for a funeral or memorial service.

Offer repeatedly—Instead of saying, “If you need anything, call me,” continue to be present and to ask specifically if you can assist with laundry, yard work, childcare, or food preparation.

DURING: Be there. Studies show that dying patients in hospitals need more care at the end of life, but often receive less.

Touch and talk—The last two senses to diminish are hearing and sensation, so dying people can often hear, though they may be too weak to respond to questions or requests. Tell them what you want them to know and refrain from saying negative things in

their presence. Hold the patient’s hand, tell them who is in the room, who is on the way to visit, or what day and time it is.

Allow time alone—Offer to provide time alone with a loved one without others in the room, to finish unfinished business, say good-bye, or just be in silence without interruption.

AFTER: Be there. You may be the one person who provides care to the family.

Assist with arrangements—Most people have no idea what happens at the time of death and after. You can assist with these questions and answers or serve as a liaison between the family and hospital staff. Decisions need to be made about funeral home, services, disposition of the body, possible organ/tissue donation.

Walk family to the car—The longest walk in the world is from the room where you have left your loved one, or watched them leave with the funeral home, to the car that is now taking you to an emptier house. At least ask to be certain the family member (especially if alone) is *able* to drive or get home, and provide some assistance if not.

Be there long term. Most people will want the family to hurry through their grief. Assure them the meter is not ticking. This process will take as long as it uniquely takes them. Call to check in with them one, three, six, nine, and twelve months *on the date of the death*. Ask if you can be there to listen, to go for a walk, get coffee, or just be present on the phone.

Self-Care for the Caregiver by Michael Weinraub

A life-threatening disease affects more than just the person who is ill—it has an impact on his or her caregiver as well. Although it is hard, you can achieve a balance between meeting your responsibilities as a caregiver and taking care of your own needs.

The following ideas may help.

Find someone to help you. Home-care providers can offer counseling, help with household maintenance, and many other services. Another option is respite care—temporary care that gives caregivers a break. Getting professional help isn’t always easy and can be expensive, but provider networks are growing. Taking the initiative to identify what is available in your community is an important first step.

Make time for yourself. If you don’t set limits, the burden of care will eventually wear you out. In his book *The Helper’s Journey*, Dale G. Larson emphasizes the importance of relieving the body of stress, what he calls “changing the oil.” Exercise, meditation, and relaxation all help provide relief.

Strengthen your support system. Staying in touch with people who care about you can have a beneficial impact on your outlook. In addition to reaching out to family, friends, and coworkers, support groups help many people. Your local Area Office on Aging or a religious institution in your community can help you to locate a group that’s right for you.

For more information, contact the National Family Caregivers Association at www.nfcares.org

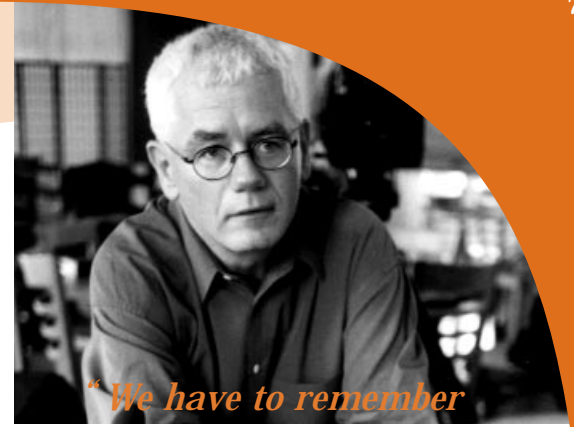
Hospice

Historically, hospice meant a way station, a place of hospitality where travelers could stop for rest and refreshment before continuing on their journey. Today, hospice is not a place, but the name for an interdisciplinary program of care that provides palliation (relief from symptoms) as well as emotional and spiritual support to terminally ill people and their families and friends. Hospice assists families and friends in adjusting to the patient's illness and death. The patient and caregivers together are considered the unit of care. It is available in hospitals, nursing homes, the patient's home, or in specialized care facilities.

Hospice care emphasizes enhancing the quality of life and preserving the patient's sense of dignity and self-worth. This includes helping to provide the terminally ill person with an alert, pain-free existence when possible; emphasizing patients' roles in decisions regarding their plan of care; and assisting them in their desire to stay at home under the care of family, friends, and visiting professionals.

Hospice medical care focuses on pain and symptom control and other supportive measures. It is an alternative to treating the patient with aggressive medical regimens, which may no longer be desired nor effective.

For more information on hospice, ask the social worker in your hospital, contact the Hospice Foundation of America, www.hospicefoundation.org or 1-800-854-3402, or go to www.nho.org for the National Hospice and Palliative Care Organization's electronic hospice locator.



"We have to remember that each of us has the resources within us to embrace someone else's suffering as our own."

*—Frank Ostaseski, Director,
Zen Hospice Center*

When a patient has only months to live, the decision-making process for physician and patient under hospice care focuses on how to enhance the quality of the patient's remaining time.

Hospice is not for everyone—either at the time of possible admission or during the course of hospice care. No one should be pressured in any way to be admitted to a hospice program or to remain in one against his or her wishes. A patient/physician decision to reactivate aggressive curative therapy or seek long-term remission through medical interventions will be respected. Patients are always free to withdraw from hospice care.

Adapted from material by the Metropolitan Hospice of Greater New York.
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Issues for Further Consideration

1. What does Myra Christopher mean when she says, "the 'business' of dying is something best done at home?"
2. What ethical or religious questions are raised for you when you consider whether you would use artificial measures to prolong life? Are there any spiritual questions?
3. What kind of professional and non-professional help might people need in order to take care of a dying loved one at home?
4. How has your family dealt with dying and death? What are some of the cultural traditions or rituals that your family and friends call upon to help them deal with dying and death?
5. What kind of help is available in your community?

Program 2

Certificate of Attendance

“On Our Own Terms” Moyers on Dying

This is to certify that _____
has completed the following inservice or self-study video and learning packet designed
with the continuing education standards of the Minnesota Board of Nursing in mind. It is
the responsibility of each professional to determine if this meets his or her relicensure
requirements.

Program Title: Program 2: A Different Kind of Care

Presenter:

Name of Program Facilitator, Degree License

Title of Program Facilitator

Name of Sponsoring Organization

Date:

Time: Two contact hours

Location:

Name of Sponsoring Organization

Address

City, State, Zip

Signature of Program Facilitator

Date

A Different Kind of Care

“A Different Kind of Care” reports on the evolution of a unique kind of care—commonly referred to as “palliative care.” Leaders in this movement address a full spectrum of pain management and symptom relief—including physical, psychological, and spiritual issues because suffering can have many sources. As “Steve’s Story” shows, skilled palliative-care professionals know that even if people can’t be cured, many might still be helped to heal.

Steve’s Story by Ira Byock, M.D.

When the hospice team met Steve Morris, he was dying hard. Struggling for every breath, he was unable to walk without gasping for air, yet unable to sit still because of the anxiety that defined his life. Steve was scared of dying; he suffered through every waking moment.

By vocation Steve had been a lineman for the phone company before a heart attack and emphysema forced his retirement. By avocation, he was a real Montana cowboy, living for his horses, winning numerous riding competitions and the affections of many for his willingness to teach horsemanship to any child eager to learn. In appearance and in his life-long smoking habit, Steve was also the prototypical Marlboro Man. He was a man’s man, not one to express emotions, or even admit to having them. Often, work and his horses had come before relationships and family.

Now he was at the end of his rope. Specialists had exhausted every hope, including the lung transplant he had desperately sought. Steve was the one dying, but he was not the only victim. His wife Dot was his constant companion, nurse, handmaiden, and co-sufferer. If she was out of sight for more than a minute, he would ring his bell or shout in his panicked, muffled voice, “Dot. Dot!”

It took our hospice team two weeks to gain Steve’s confidence through a combination of pharmacy, counseling, and pragmatism. We used meticulous medication management, relaxation tapes, suggestions regarding placement of his recliner, and volunteers to spell Dot so she could shop for groceries, see her own doctor and get a few moments of rest. These efforts, drawing on the experience and resources of palliative care, helped diminish—at least slightly—Steve’s breathlessness and paralyzing fear.

As we learned more of Steve’s personal history, we realized that his anxiety stemmed in part from the fractured nature of several key relationships and from his complex, conflicted family life.

One Thursday, while I was visiting Steve and Dot at home, I taught him about the Five Things. “Years ago, a nurse taught me that before any significant relationship was complete, people had to say five things. ‘Forgive me.’ ‘I forgive you’—because if this was a significant relationship there will always be some history of hurt. ‘Thank you.’ ‘I love you.’ ‘Good-bye.’”

“Those are really good, doc.” Steve responded with unexpected enthusiasm. “Write those down for me, will ya?”

At my next scheduled home visit, Steve was sitting up, awaiting my arrival. He and Dot excitedly related the events of the past weekend. On Sunday their children and grandchildren had come over for dinner. At the table, Steve had announced he had some things he needed to say. He began, “You know, the doctors tell me that this emphysema is finally going to get me. And I know I haven’t always been the best father, or husband, but I love you all and there are some things I want to say.” With his eyes on my handwritten list, he recited the first four of the Five Things in his own words.

The effect was remarkable. Although his anxiety did not disappear, in the wake of his remarks, its grip weakened. A tenderness and obvious affection was now evident in the family’s interactions that had not been present for years, if ever. Steve’s life didn’t become easy, but it became less anguished.

Ironically, as he faced life’s end, Steve said he was happier with himself than he could ever remember being. Paradoxically, in the process of dying, he was healing and becoming well within himself.

Complementary Care

In recent years, alternative therapies have become increasingly popular in end-of-life care because of their potential to improve the quality of life as death approaches. Used in conjunction with traditional medical care, these complementary treatments can alleviate pain, contribute to healing, and enhance a sense of well-being in patients. Access to complementary care is growing in hospitals and health-maintenance organizations across the country. Complementary care includes:

Chiropractic Medicine Homeopathy Meditation Nutritional Therapy Acupuncture Massage Music Therapy

What a Family Goes Through by Joanne Lynn, M.D., *Americans for Better Care of the Dying*

Serious illness and death, like birth, define what it means to be a family. Some families grow closer, while some grow bitter, and some just endure. Some revisit old memories while there is still time. One thing is certain: Everyone changes as we experience the serious illness and death of someone who has meant a great deal to us.

Most families feel as if their loved one became seriously ill “all of a sudden”—even if, as they think it over, they realize that the person had been sick for months. Often, some event suddenly makes everyone realize just how serious the situation has become: The patient is hospitalized, or becomes too weak to do some essential task at home; or a doctor or nurse makes a blunt statement. But few people feel prepared for a family member’s last illness, and often changes must be made quickly.

Some of the necessary accommodations are structural—how to put a bed and bathroom on the entry level, or how to make a shower stall out of a tub enclosure. Some changes aim to enable a family member to provide care—leaving a job, moving in with a daughter. Most changes that enable family caregiving also require emotional adjustments—“Mom won’t be with us long,” or “Pop will never be the same.” The stress and disruption require some thoughtfulness and compassion for one another.

A Nurse Looks at Comfort at Home by Edwina Taylor, C.R.N.P.

“You’re going home.” What a scary/exciting thought for the dying person and the caregiver! Here are some tips for comfort care once the dying person gets home.

In matters of personal preference, take cues from the patient. He knows best whether he wants to sit up or lie down; come to the table or have a snack in bed; nap or watch TV.

Offer choices of food and don’t offer huge amounts. He may not want much to eat. The dying person’s diminished sense of hunger and thirst is a way for the body to know when to slow itself down and stop. Remember what entertainment he formerly enjoyed and offer those options.

While no one wants to upset someone who is dying, the dying person’s greatest fear can be isolation. Ask the dying person, “How are you doing?” If he wants to talk about his condition, he will say so. If not, stick to normal conversation. The dying person is the *person* he has always been, and appreciates being treated in a normal way.

Ask, “What can we do to make you feel better today?” and be prepared to do whatever the patient asks. Events, such as a religious ceremony, civic presentation, or a child’s birthday party may be staged at home. A trip to the garden, a tub bath, or a visit with a favorite friend or relative can be very meaningful for both the dying person and the caregiver.

Inevitably, someone says something harsh or selfish that can drive family members apart forever, unless all can forgive.

Family members usually learn to endure these rough times, and they have questions about what to expect in the future. How long will Aunt Jane live like this? What will the end be like?

It is very frustrating to encounter the usual evasive answers from doctors and nurses, but part of the reason for that evasion is because predictions are quite uncertain. We have found that families get better information if they recognize that these are very hard questions. Sometimes, it is more effective to ask questions like this: “Given how sick Aunt Jane is today, what could happen in the next few months? Would it be surprising if she lived for as long as six months (or whatever time seems reasonable)?” Likewise, when possible, find an experienced home-care or hospice nurse, or an older physician, and ask for some specifics: “We really need to be prepared for what is to come. Will Dad get so sick he doesn’t even recognize us? Is he likely to have any pain? What kinds of symptoms and crises are likely to arise as this illness gets worse?” (See other suggestions in *Handbook for Mortals*.)

Family caregiving is a challenge, and it most often falls to spouses, daughters, and daughters-in-law who may give up income, career advancement, and personal well-being. Family decision-making for a dying patient can be divisive and frightening. Family caregiving can also greatly deplete financial resources. Communities need to rally to help families in this situation, both directly in their neighborhoods and collectively through supportive provisions in tax laws, community services, employer flexibility on leave, and employment opportunities for caregivers returning to work.

Nevertheless, family caregiving is also a deep and abiding affirmation of love and shared humanity. Many family caregivers feel that “this is the hardest and the most important thing that I have ever done.” Family members involved in caregiving ordinarily have less guilt and doubt after the death; they know that they did all they could to ease the patient’s suffering. In a world that often seems harsh or superficial, there may be peace and meaning in giving your brother a bed bath, or holding your sister’s hand as she lives her last days. Care given with affection and shared grief cannot be duplicated—not by a machine nor by a stranger. It is love made manifest.



photo © Sylvia Plachy

“Pain is a more terrible lord of mankind than even death itself.”

— Albert Schweitzer, M.D.

Palliative Care *by Ira Byock, M.D.*

Palliative care is comprehensive care for people with life-limiting illness. It is a team approach focusing on the needs of ill people and their families. Palliative care is valuable at any time during a serious illness; one doesn't have to be dying to benefit. Patients can continue to fight their disease, while palliative care focuses on improving their quality of life. Hospice is one form of palliative care. Like hospice, palliative care can be provided in a variety of settings including hospitals, nursing homes, and a patient's home. Currently, in order to receive hospice care, a doctor has to certify that a patient's life expectancy is six months or less and both patient and doctor must agree to forgo further surgery, radiation or chemotherapy directed at prolonging life. Palliative care attempts to avoid these conditions and seeks to serve people earlier in the course of illness.

Physical comfort is the first priority for palliative care, but it is not the ultimate goal. Relief of pain, breathlessness, or other physical discomfort is precious in its own right. But this respite also allows people the time and energy needed to attend to deeply personal questions that serious illness imposes. “Now that I am sick and not likely to get better, what matters most?” “If I were to die suddenly, what would be left undone?”

Palliative care is distinguished among clinical specialties in acknowledging that dying is normal—part of the life of every individual, and every family. Relatives and close friends are deeply affected by their loved one's illness and approaching death. They are often inundated with the day-to-day, moment-to-moment, practical, and difficult tasks of caregiving. Improving the experience of living for seriously ill patients and their families is, therefore, another primary goal of palliative care. And because a family's experience of terminal illness and a loved one's passing does not end at the moment of death, palliative care extends support for the family in their grief.

A typical hospice or palliative-care team may include one or more doctors, nurses, social workers, home health and

bathing aides, pharmacists, chaplains, and physical and occupational therapists. Increasingly, teams also draw upon the skills and services of complementary therapists. Trained volunteers are critically important resources of palliative-care teams. They may help with house-keeping, perhaps cooking or running errands, or making an afternoon outing possible. The essential service volunteers provide is the gift of their time and undivided personal attention.

Dying is almost always hard, but it need not be horrible. With skillful guidance, hospice and palliative care can help people deal with the stress of advancing illness and disability and the inherent sadness of dying. When a measure of comfort is assured, people often find valuable opportunities: a chance to communicate their feelings to key people in their lives; a chance to reconcile previously strained relationships; a chance to tell treasured stories; a chance for healing the pain of one's past; and a chance to come to peace with one's life-long expectations and frustrations. These are opportunities to explore meaning and to connect to a spiritual realm, not out of a sense of desperation, but because these have become the things that matter most.

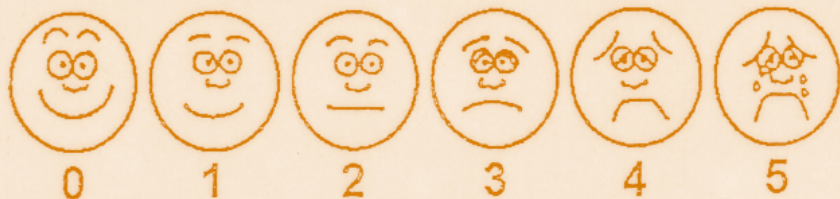
The process of life completion can enrich the quality of the ill person's remaining days and affect the lives of family members for years to come. While the effective management of symptoms remains fundamental, palliative care strives to promote opportunities for the person and family to grow, individually and together, during this poignant and often precious time of life.

If you think you or a family member would benefit from hospice or palliative care, you are probably right! Ask your doctor or nurse to help. Even when it is not possible to add many days to life, the opportunity exists to add life to one's days.

Photo © Sylvia Prachy



PAIN SCALE



A pain scale like this is often used in healthcare settings to help patients describe their level of pain or distress. Even when patients are unable to speak, they can point to the appropriate face.

Talking with Your Doctor *by the Rev. Chuck Meyer*

Just as you need information from your doctor, your doctor needs to know some things about you. Dr. Sean Morrison, co-director of the palliative care program at Mt. Sinai Medical Center in New York City, suggests the following:

1 Tell your doctor everything you know about your illness. What have you learned from other physicians, from other patients, or from the media? It is important that both physician and patient have the same understanding about the illness so they can agree on the course to follow together.

2 Your physician needs to know how much to tell you and who to turn to for help with decisions. Do you want general information or the many details of disease progression and treatments? Will you make all your decisions or do you want someone else—a family member, friend, or a surrogate named in an advance directive—to make them for you?

3 The doctor needs to be certain the diagnosis, prognosis, treatment, and comfort options have been clearly explained to you. Is there anything that you need described further so you both understand the outcome of the disease before you plan to manage it together? No question is too basic, embarrassing, or foolish to ask.

4 In evaluating treatment options, the physician needs to know what things are most important to you. What makes life worth living? What conditions might be worse than death for you? What would you like to accomplish in the next months? The doctor must know about *your* values and your quality-of-life standards.

5 Your physician should know when you feel any concern about your care, your treatment, or your interactions with other physicians. Patients and families need to feel assured that their physician will be present and supportive with them throughout the entire process.

If you do not know your doctors, there are chaplains, social workers, patient representatives, and ethics committees to help with questions and decisions, or to help you deal with your physician or institution. You need never be alone in your decision-making, or at any point in the journey through illness.

Pain Management *by Richard Payne, M.D.*

Patients and families fear physical pain related to cancer, AIDS, and other disorders as much as they fear the diseases. Sir Thomas Aquinas has said, "Pain is the greatest physical evil." This is the bad news. The good news is that modern medicine has the tools to conquer pain.

Strong painkillers such as morphine can be prescribed alone, or combined with other medications to control many of the most severe forms of pain. Furthermore, doctors can often manage the side effects of these medications, alleviating patients' and families' fear that the cost of good pain relief is being "doped up." We can treat pain and improve your ability to function and relate to your family.

Physical pain may have both a physical and a non-physical cause. Emotional, spiritual, and psychological distress can lead to or exacerbate pain, so treating the whole person is mandatory. In recognition of its multiple dimensions and complexities, and the unique ability of unmanaged pain and suffering to destroy the life and soul of individuals, pain management is now practiced as a special area of expertise in modern medicine.

Unmanaged pain is not heroic and it does not spare your family. It steals energy that is needed to continue with life and is unnecessary. Find the experts on pain management in your community to help your doctor help you.

Issues for Further Consideration

1. How can saying the five things mentioned in Steve's story—"forgive me," "I forgive you," "thank you," "I love you," and "good-bye"—help ease anxiety at the end of life?
2. What are some differences between attempts to cure and efforts to heal?
3. What are the advantages of palliative care provided by a team, rather than by one caregiver?
4. If you have a doctor you see regularly, what are the benefits of discussing the care you want at the end of life? What can you do if you feel your doctor is not listening? What are the benefits of having advocates for your care?
5. What are some of the ways that family members and friends can help to relieve the suffering of a dying person? How can people in your community help?

Program 3

Certificate of Attendance

“On Our Own Terms” Moyers on Dying

This is to certify that _____
has completed the following inservice or self-study video and learning packet designed
with the continuing education standards of the Minnesota Board of Nursing in mind. It is
the responsibility of each professional to determine if this meets his or her relicensure
requirements.

Program Title: Program 3: A Death of One's Own

Presenter:

Name of Program Facilitator, Degree License

Title of Program Facilitator

Name of Sponsoring Organization

Date:

Time: Two contact hours

Location:

Name of Sponsoring Organization

Address

City, State, Zip

Signature of Program Facilitator

Date

A Death of One's Own

Dying well, to many, means control over choices to be made as we die. We fear dying in pain; we fear that too much will be done to keep us alive, or we fear that not enough will be done. "A Death of One's Own" looks at the issues surrounding efforts to control how we die and the implications for families, institutions, and communities.

Hard Choices

Physician-Assisted Suicide by Gerald Jonas

Facing death calls for hard choices, whether you are a patient, a family member, or a professional caregiver. With modern medicine able to prolong life through a battery of invasive procedures like breathing, feeding, and hydration tubes, most people will have to decide when invasive life-support procedures are called for. If started, when should they be discontinued, and who should decide? What role should palliative care play in end-of-life decisions? How can patients be sure of getting the pain medication they need to remain comfortable? Will the medication relieve their pain at the cost of their awareness? What relief can hospice provide and when should it be called in? Is terminal sedation an understood option and is it appropriate? When, if ever, should physician-assisted suicide be an option?

The end-of-life issue most in the news these days is physician-assisted suicide (PAS). While Oregon is the only state that has legalized PAS, the issue concerns all Americans. An April 1998 article in *The New England Journal of Medicine* reported that one of five doctors with experience in caring for patients with life-threatening illness has been asked by patients for assistance in speeding their deaths.

The United States Supreme Court, along with many religious authorities, including the Roman Catholic Church, agree that letting nature take its course—by foregoing or discontinuing invasive life support for dying patients—does not violate legal or moral strictures against taking a human life. Some people, however, fear living with suffering and being incapacitated even if life support is never required.

For such people, advocates of PAS see physician-assisted suicide as an act of mercy. But even the most passionate defenders of PAS agree that it must be carefully regulated to prevent abuses. For example, Oregon's "Death with Dignity Act" applies only to mentally competent patients who have been certified as having less than six months to live by two different doctors. Patients must request assistance twice, once in writing and then verbally, 15 days later.

Opponents of PAS maintain that it is never right to cross the line between letting someone die of natural causes and actively hastening death. For many, this is an absolute religious principle. Others believe that, even if closely regulated, PAS will lead to patients being pressured to end their lives by relatives, institutions, or the state itself. While they recognize that there are patients whose pain cannot be managed, opponents also argue that patients who seek PAS may be suffering from treatable distress like depression, fear, or unrecognized pain. Some doctors refuse to participate in PAS on grounds that it is a violation of the physicians' Hippocratic Oath, which enjoins them above all to "do no harm."

Although the debate about PAS is often framed in either/or terms, advocates of palliative care claim to find a middle ground. Compassionate concern for others' pain and suffering, they say, should begin with a commitment to keep dying patients as comfortable and alert as possible. In fact, they point out, when good hospice care is available, fewer patients choose to hasten death.

For more information about the debate surrounding PAS, read *At Death's Door: What Are the Choices?* prepared by Public Agenda for National Issues Forums. To obtain a copy, call (800) 228-0810.



Jim Witcher, ALS patient, and his wife Susie talk with Bill Moyers.

Finding Peace

How Community Helps

by Myra MacPherson

A seriously ill person is affected not only by friends and family but by the larger community as well. And yet the impact of the larger community on the person is often ignored. How co-workers and employees, members of the PTA or the exercise class, the religious community, or school treat the person can either be jarring and stressful or provide moments of love and a measure of peace.

What can this extended “family” do? First, do not run away. Remember that grieving begins with the day of diagnosis. A roller-coaster life of treatments and good and bad times can make the strongest person feel bereft. Support from the entire community is vital. Employers and co-workers can make the workplace a sanctuary. The employer should set the tone for the staff: assure the person that his or her job will not be lost, treat the person as normally as possible but be lenient about doctor appointments, respect the person’s confidentiality, and/or provide the opportunity for confiding and counseling. The co-worker who continues to ask the person to lunch or go out for a drink after work is giving a gift of normalcy.

When a child’s parent is seriously ill, teachers and principals must recognize that grades may slip and the child may withdraw. Children need to vent feelings freely, which often cannot be done at home. School counselors should initiate the opportunity for them to confide. Classmates may need guidance on how to treat their friend.

Faith communities can offer respite care, help with meals or childcare, or can provide comforting rituals. The friend or co-worker who anticipates a need is far better than the one who waits to be asked. Cut the lawn, buy the groceries, take the children to dinner, relieve the spouse. And during the final days, a friend or co-worker can provide the greatest gift imaginable: taking a simple course on how to become a hospice caregiver. Knowing how to help administer to a friend’s daily needs and relieve the family of duties provides a measure of peace not just for the patient, but for the friend who knows that she or he has done all that can be done to help provide a peaceful and painless end.

Hospice patient with friend



photo © Doug Barber

An Eternal Moment

by Rob Lehman

After years of running and meditating, of practicing mind-body-spirit disciplines daily, the first thing that I did after learning that my body was filled with cancer was to buy a pack of cigarettes and a six-pack of beer and head for the beach.

Initial terror was followed by surrender as my fear gradually took on a deeper, more inward character. I walked alone a lot. I prayed, recited my favorite Psalms, and slowly began to accept that in the next few months I might die. Soon I became aware of a deep sadness. Yet even this gave way eventually to an unexpected joy. Boundless love from family and friends was the mysterious gift that allowed me to let go of my grip on outer life and befriend my inner life, and to see—with Walt Whitman—*the multitudes contained within*.

It is this “one who sees,” this more personal and yet also more universal Self, that I have come to know through my experience with cancer. As I learn to observe the many dimensions of my life from its unobstructed perspective, I find that I spontaneously accept—with profound peace—the wholeness of all life. When we truly accept our wholeness, we begin to experience life as beyond time, as eternal. We notice this eternity in the present moment, as St. Therese explained, in all the small things we do with great love. We learn that the present, in all its glory, is the eternal moment.

How to Talk About End-Of-Life Concerns

by Joanne Lynn, M.D., *Americans for Better Care of the Dying*

It is hard to talk about dying, death, and bereavement. Virtually everyone wants those conversations to have happened, but no one wants to “have that conversation today.” Talking about death seems at first to make it more real, more threatening. Afterwards, though, most people find that talking ends up being very helpful and reassuring. Having some strategies may help.

First, push yourself to take the openings that come up. When Dad says, “I think the doctor thinks things are not going well,” the family member is prone to say, “Don’t talk that way. Everything is going to be fine.” Instead, try, “Really? Why do you think that?” or try “What do you think the doctor is trying to say?” (Other sets of openings and responses are in *Handbook for Mortals*, p.11.)

Second, you should talk naturally about a time when the person will no longer be alive, even if at first you talk about some unreasonably long time into the future. “Mom, is there something that you want your granddaughter to have on her wedding day?” Often, a sick person will take the lead gratefully and say something like, “I wish I could see that, but I don’t think I’ll even see her at Christmas this year. I hope she finds someone half as good as your father. I wonder—if I could find that apron that my grandmother gave me when we married, would you keep it and give it to her then?” Obviously, that opens the gates to all sorts of conversations over the ensuing hours and days.

Third, talk about the patient’s current hopes and fears. Ask something like, “Do you think this pain will get worse?” or “What do you think will happen as time goes on?” When you and the patient are not sure what you face, set up a way to find out (like letting the physician know that you want to discuss this at the next visit).

Remember, you need not use blunt or cold terms. Many Biblical phrases, poetry, songs, and metaphors deal with dying. And you need not talk of death most of the time. You can also reminisce, talk about daily life, and talk about plans and hopes.

How can you start? First, recognize that you or your loved one is still living and has a past, a present, and a future. Talk some about the past—share stories about what is important or what shaped this particular person or family. Talk some about the present—what is going well and what is going badly for patient and family. And, even though it may seem awkward, talk about the future—what hopes and dreams lie there, what practical problems, and how long the patient may live. In addition, you might find it useful to consider a list of important issues that are usually appropriate to consider.

(see “Talking About the Future” on page 15)

What to Talk About...

There are specific issues that should be decided in advance. Without advance planning, emergency responses to sudden changes in the patient’s condition can be inappropriate. Virtually every seriously ill patient and his or her family should have decided the following issues.

1. Proxy—Someone needs to have the authority to speak on the patient’s behalf when he or she is too sick to do so. Any hospital, nursing home, hospice, or home care agency can help with a form called a “healthcare proxy” or “durable power of attorney” that allows the patient to name someone as their proxy or surrogate in a legally binding way.

2. Resuscitation—Ambulance technicians and hospital personnel will immediately try to resuscitate anyone who collapses and is near death. However, resuscitation may not be desired if the collapsed person has been quite sick with an illness that is expected to worsen and lead to death. In order to keep anyone from trying resuscitation, the patient should ask his or her physician to write an order “not to attempt resuscitation” (often called “DNR” for “Do Not Resuscitate”). This order does not affect whether the patient can get hospital care or other treatments. Most states now provide a way to have an order against resuscitation put into effect when the patient is at home or anywhere else.

3. Hospitalization—Many seriously ill people come to the point where they cannot imagine a surgery or test that they would still want to have. At that point, they should ask their physician’s advice on avoiding hospitalization, except to relieve suffering (e.g., to set a broken bone or relieve shortness of breath).

4. Specific Treatments—Many patients fear specific treatments such as breathing by machine, having a kidney machine, or having artificial nutrition or hydration (“tube feedings”). The merits of these should be discussed in advance. If the patient wants to forgo these treatments, he or she can write that down. If the patient is unclear about their merits, he or she can opt for a “trial of treatment.” For a limited time, the treatment would be carried out. That trial allows the patient, family, and care team time to make a final decision. The treatment can then be stopped or continued based on how the patient responds to treatment.

The DNR (“do-not-resuscitate”) MedicAlert® bracelet is imprinted with the MedicAlert® emblem on one side and DNR wording on the other. It is backed by a fully staffed 24-hour Emergency Call Center and recognized as a valid pre-hospital DNR order by emergency medical services in eight states: Arkansas, California, Indiana, Kansas, Maryland, Nevada, New Mexico, and Wisconsin. “DNR-EMS ON FILE” or similar wording is engraved for residents of other states.

For more information about DNR and advance directives repository services contact MedicAlert® Foundation at 1-800-432-5378 or on the Web at www.medicalert.org.

photo © Geraldine Rubio



5. Financial Issues—All patients need to consider the effects of treatment costs on their surviving family, the bequests that the patient wants, and how to deal with other costs. Often, a financial planner, lawyer, or social worker really helps. Your professional caregivers, local hospice programs, local aging services (Agencies on Aging, for example), and your friends will often have suggestions of people who are knowledgeable, affordable, and helpful. While some people consider these issues impolite to mention, a little planning can prevent financial chaos for the bereaved family.

6. Events Near Death—As patients and families converse about the upcoming death, they may find they have strong ideas of how things should proceed. It can be helpful to plan who will be with the patient at the time of death or shortly thereafter, who will be notified, how the memorial services will proceed, and so on—in as much detail as possible.

Writing It Down Advance Directives

- Think about what you really want to happen, given your medical condition and your family situation.
- Talk about your choices with those who matter to you and who will be around you when problems arise or death comes close.
- Have your doctor or nurse help you write down your wishes in ways that laws reinforce. In general, state laws allow for two kinds of written advance directives—naming a decision-maker (or “proxy” or “surrogate”), and giving specific instructions about treatment. Naming a surrogate is especially important if you live in certain states or if your family situation is confusing as to who would be “next of kin.”
- Write down at least your spokesperson and your most important choices, using the formats accepted in your state’s advance-directive statutes (see www.choices.org)—living will, durable powers of attorney, and health care proxy laws.
- For a “checklist” form, go to Five Wishes on the Web at www.agingwithdignity.org.

Talking About the Future

Pointers on conversations about the future between seriously ill patients and those who love them:

- Use language that everyone is comfortable in using.
- Take your time. Pauses and shared quiet time can communicate too.
- Encourage the patient to talk in his or her own way.
- Check what one another understands and feels.
- Talk of the time near death and just after in a natural way.
- Talk of practical matters and also of emotions and spiritual issues.

Issues for Further Consideration

1. If you were to become terminally ill, would you want to choose your time of death? How much input would you want a doctor or other healthcare provider to have if you could no longer speak for yourself? Have you shared your thoughts with your family?
2. A doctor’s oath is to “do no harm.” How can a doctor best abide by this oath in the final stages of terminal illness?
3. What issues are raised for you when you consider terminal sedation, physician-assisted suicide, and dying assisted only by palliative care?
4. What choices about death do terminally ill people, their loved ones, and doctors have in your community? Do you feel they are sufficient or insufficient? Why?
5. Why might disabled, poor, and mentally ill people oppose physician-assisted suicide? Is legalizing physician-assisted suicide good public policy?

Program 4

Certificate of Attendance

“On Our Own Terms” Moyers on Dying

This is to certify that _____
has completed the following inservice or self-study video and learning packet designed
with the continuing education standards of the Minnesota Board of Nursing in mind. It is
the responsibility of each professional to determine if this meets his or her relicensure
requirements.

Program Title: Program 4: A Time to Change

Presenter:

Name of Program Facilitator, Degree License

Title of Program Facilitator

Name of Sponsoring Organization

Date:

Time: Two contact hours

Location:

Name of Sponsoring Organization

Address

City, State, Zip

Signature of Program Facilitator

Date

Program 4

Objectives and Post Test

“On Our Own Terms” Moyers on Dying

OBJECTIVES

At the end of this program, participants will be able to:

- List two problems in end of life care,
- Define grief,
- List four components of a spiritual history.

POST TEST

1. List two problems in end of life care.

2. Define grief.

3. List four components of a spiritual history.

A Time to Change

“A Time to Change” features crusading individuals who are working to change public policy to improve care of the dying. They are creating models for change that deal with issues including insurance coverage, the training of doctors, and building communities of volunteer caregivers to relieve the burden on families of the dying. Successful programs are already being developed and tailored to the specific needs of different communities and unique individuals. In this program and in the following story, we visit Birmingham, Alabama, to see how services can be provided in even the most challenging circumstances.

Lois Johnson and Balm of Gilead by Gerald Jonas

Among Birmingham, Alabama’s 21 hospitals, only one treats people regardless of their ability to pay—Cooper Green. The hospital is also home to Balm of Gilead, a hospice and the first and only palliative care unit in Alabama. It is unusual because it serves the people who fall between the cracks of Medicaid and Medicare—the working poor and the uninsured.

Under medical director Dr. Amos Bailey, Balm of Gilead works to ease the burdens of terminally ill patients and their families, providing them a full range of care from pain and symptom control to spiritual guidance. Its name recalls the words of a popular hymn: “There is a balm in Gilead to make the wounded whole/ There is a balm in Gilead to heal the weary soul.” Its program is multidisciplinary, drawing on a cooperating network of community agencies and institutions.

It is a constant challenge for the hospice care team to find a place for Balm of Gilead’s patients to live out their last days. Patients may not have a full-time caregiver at home, their loved ones may not be capable of taking care of their needs, or they may be homeless, with no family support to speak of. Bailey’s team must then look for an alternative. Options include nursing homes and boarding houses. It is important for the team to be able to stay with the patient, caring for him or her in whatever setting necessary and providing a continuum of care from institution to institution.

One patient who benefited from Balm of Gilead’s help was Lois Johnson. On the morning of May 5, 1999, she told a nurse, “You know, it’s going to be all right.” The 58-year-old formerly homeless woman was moving from the hospital to a boarding house associated with Balm of Gilead.

When she was 16, Ms. Johnson was placed in a mental hospital; she spent the next thirty years in and out of institutions. Later, she chose to live on the street rather than suffer the emotional strain of staying with her mother and sister. When she developed cancer, her mastectomy and chemotherapy proved ineffective and the disease spread to her lungs.

Bill Moyers and Dr. Amos Bailey at the Balm of Gilead reception area



photo © Sylvia Plachy

Though she had always had trouble establishing relationships, the warmth of palliative care specialists like Edwina Taylor, a Balm of Gilead nurse with 29 years of experience, won her over. Before she left for the boarding house she was assured that she would continue to get the same level of care there as in the hospice unit with regular visits from a Balm of Gilead nurse and help with her many medications. She smiled through her tears when Edwina Taylor added, “And if you ever need to come back here, you know you’re welcome.”

In her third week at Ms. Hill’s, she fell into a coma and was brought back to the Balm of Gilead unit at Cooper Green. She died peacefully the next day, watched over by Edwina Taylor and her colleagues. Without the care provided in all settings by the Balm of Gilead program, Lois Johnson would almost certainly have died alone and in pain. In her final days, she kept praising the Lord for delivering her into such compassionate hands: “I never thought people was so nice, I didn’t know people cared so much.”

Asked the most important thing she has learned during her years of caring for the sick and dying, Edwina Taylor doesn’t hesitate a second: “Nobody wants to die alone.”

Diversity in Dying

by Richard Payne, M.D.

Ideally, dying well means not only passing away free from physical pain, but also having an opportunity for closure with one's life, to say good-byes, and to be in the company of friends and loved ones.

These goals are universal. However, for minorities, particularly for patients and families coming from poor and medically underserved communities, there are other issues to consider when dying. Will my cultural, religious, spiritual, and personal values be respected? How do I understand the discussions about medical futility, advance directives, and palliative goals of medical treatment from a perspective that is influenced by limited access to curative treatments? How do I understand the concept of surrogate decision making, when my family and cultural styles encourage group decision making? Is the offer of palliative care really a code word for further denial of access to care? How does palliative care increase my options for end-of-life care and the goals of dying well?

These profound questions influence perspectives on the quality of end-of-life care and the meaning of "dying well." To make dying well an "equal opportunity" enterprise in this multicultural society, we must consider these questions more fully than space allows for here. We must have healthcare providers who are of similar cultures and sensitive to multi-racial cultures and ethnicities. Addressing these and other questions can ensure that the concepts of palliative and hospice care are "good fits" for the entire society.

Grief

by Kenneth J. Doka, Ph.D.

What is grief?

Grief is a reaction to loss. While we often associate it with death, any loss such as divorce or job loss can engender grief reactions. When such losses are not acknowledged, recognized, or supported by others, that grief can be said to be *disenfranchised*. The meaning attached to the loss will naturally affect the intensity of grief reactions.

In cases of life-threatening illness, patients, families, and friends may experience *anticipatory grief*. Anticipatory grief is not only a grief response to an anticipated loss of life, but to all the losses that are experienced in the course of the illness, such as the loss of health, functions, jobs, and other social roles.

How is grief manifested?

Grief is manifested in a variety of ways. Grief responses can include emotional reactions such as intense feelings of sadness, guilt, anger, or loneliness. Grief may affect individuals physically, manifesting itself in bodily aches and pains. Grief can affect individuals cognitively. Grieving individuals may find it difficult to concentrate or may constantly review the loss. Spiritually, individuals may struggle with their faith or philosophy as they try to find meaning in the loss. Grief may also manifest itself in the ways individuals behave.

Each individual experiences grief in his or her own unique way. Terry L. Martin and I, in recent work, have described different grieving styles. In the intuitive style, individuals tend to experience and express grief in the ways they feel. Instrumental grievers, on the other hand, tend to experience and express grief in cognitive and physical ways. For example, an intuitive griever may find comfort in expressing feelings, while an instrumental griever might be helped by sharing memories of that loss or participating in activities related to the loss. These styles are influenced by factors such as culture, gender, and personality.

How long does grief take?

There is no timetable for grief. Each loss has a different meaning; a wide range of factors and circumstances affects each. Many individuals experience grief as a roller coaster, an uneven process full of ups and downs. Over time, many individuals will find that pain lessens and that they are able to return to previous levels of functioning. It is not unusual that even years following a loss, events or memories will continue to generate moments of grief.



Todesangt (Death Agony) (1896), Edvard Munch.
Lithograph. Graphische Sammlung Albertina, Vienna.

*“Giving always means receiving.
Each person whom I have assisted
has given me more than I gave.”*

*—Interfaith Volunteer Caregiver,
Sedona, Arizona*

Volunteers by *Kenneth G. Johnson, M.D.*

Volunteering is an unselfish action of enormous benefit. Helping another displaces us from being in the center of our own personal universe, and affirms our sense of dignity and worth and that of the person we help.

If you can free up two hours in a week to make a telephone call or a friendly visit, give a ride to the doctor, do some light shopping, provide brief respite for a family caregiver, or change a light bulb, you will be doing what most volunteers in America do. They are simple tasks, but are powerful because they permit a person who needs such help to live with hope and dignity.

To be a volunteer does not require professional training. Most volunteers bring a trove of lifetime-acquired knowledge and skills in informal caregiving. In joining a voluntary organization, volunteers affirm and enhance these skills, allowing them to work with confidence.

Within your community, there are dozens of voluntary organizations awaiting your call. Thousands of congregations of all faiths are working together as interfaith volunteer caregivers. Hospitals and nursing homes, senior centers, day-care centers, meals-on-wheels programs, and respite and hospice programs are heavily dependent on volunteer assistance.

If you wish to volunteer, seek out an organization in your community that has a well-managed program that provides the orientation and preparation needed for you to make the most of your contribution of talent and time. You will find people who can help direct you at local agencies such as the United Way, Catholic Charities, Lutheran Social Services, local Retired and Senior Volunteer Programs, Interfaith Volunteer Caregivers programs, the Alzheimer's Association, AARP, and Regional AIDS Interfaith Networks, and through friends who are, themselves, volunteers.

Building Community Networks by *Myra J. Christopher*

Dying is not a medical event; rather, it is a social experience. To improve care of the dying will require broad-based collaborations within communities. Certainly, clinicians must be involved, but the commitment and leadership of grassroots organizations, the faith community, policy groups, and many other institutions will also be required to make the necessary changes.

In Kansas City, faith leaders have been at the forefront of building a community network to improve care of the dying. In 1998, some two dozen Kansas City priests, rabbis, ministers, imams, and others began working together to come up with practical ways to address both the spiritual and psychological needs of their congregations and assemblies.

With assistance from Midwest Bioethics Center, this group organized a community-wide initiative called Compassion Sabbath. The initiative began with an all-day conference in the Fall of 1999 that brought together more than 400 leaders from churches, synagogues, and mosques. Follow-up workshops for adult educators included distribution of a worship resource kit

filled with prayers, songs, and rituals from Christian, Jewish, Native American, Islamic and Hindu faith traditions.

Our yearlong initiative led up to Compassion Sabbath Weekend. Approximately one-

fourth of Kansas City's 2,000 congregations and assemblies participated in this community-wide celebration. Added together, about 75,000 people attended Compassion Sabbath services, nearly matching the number of people who fill Arrowhead Stadium most Sundays during football season.

Organizing interfaith activities in Kansas City is not an easy task. Our faith leaders had to work hard to identify common ground and respect the differences that exist among them. However, they have come to recognize that collaboration is a powerful tool in fulfilling their ministry to the sick and dying.

We believe this model of collaboration and network building can be successful in most communities. If you want to get involved in building an end-of-life care network contact your state end-of-life partnership or coalition. Such partnerships exist in 23 states under the Community-State Partnerships to Improve End-of-Life Care, a three-year program supported by the Robert Wood Johnson Foundation and numerous local funders. Other states have community ethics networks; agencies serving the elderly; university aging centers; and statewide hospice, cancer-pain, or healthcare organizations. Their objectives are different, but all share a vision of death with dignity that respects the beliefs and needs of the individual.

Policy Issues

by Joanne Lynn, M.D.,
Americans for Better Care of the Dying

People can't always count on receiving good care at the end of life. A typical 75-year-old can get open-heart surgery more easily than he can get heart-failure medicines or someone to come to the house to give him a bath.

Medicare and commercial health insurance arose when many patients couldn't pay for surgery. When surgery or a particular test or treatment is needed, health insurance keeps costs from overwhelming patients and families. Unfortunately, very different services are often needed at the end of life. Patients might need medications, direct personal services, symptom relief, advance-care planning, patient and family education, bereavement support, and coordination of services. Health insurance, including Medicare, was not designed to cover these services.

Hospice programs provide a remarkable contrast—they pay for all these things and generally support patients and families through death and bereavement. Hospice payment has various problems; primarily, hospice coverage is not available to most people because their prognosis is too uncertain, and a patient needs a prognosis of six months or less to live to qualify for hospice care. In addition, some hospice programs require that the patient give up on treatments and have a home and a volunteer caregiver. As a result, less than a quarter of Americans now use hospice, and then only for an average of a few weeks.

Much could be done to make comprehensive, affordable services available to all who are suffering serious and eventually fatal illness. Medicare could sponsor demonstration programs that let us all learn how to identify people in need, tailor services to their problems, and pay for care equitably. We could figure out how to pay for essential medications and certain treatments in patients' homes. We could try out strategies to have hospice and other comprehensive programs more broadly available. We could set standards for such essential elements as continuity of care, pain control, and advance-care planning—and patients (and Medicare) could refuse to use providers who do not meet quality standards.

photo © Sylvia Plachy



But to do that, we have to make good end-of-life care a *political* issue. For a long time, we have talked about end-of-life care as if it were a problem of patient rights, insensitive physicians, and denial of death. True enough, but end-of-life care is also an economic issue. We can't expect good care to be available if those who reliably provide quality care cannot make a living.

We also must not let the issue of good care be overshadowed by the debate over physician-assisted suicide. Our society runs terrible risks if we debate end-of-life issues as if they were entirely about moral and legal rights. Most patients who think they want physician-assisted suicide change their minds when they learn that hospice care is available, that pain can be well-controlled, that depression can be treated, and that families can be protected from financial ruin. It is unsettling to think that people might choose to take an overdose because the alternative is to endure unnecessary, unremitting suffering, bankruptcy, overwhelmed family members, and so on. Perhaps we should first assure the availability of reliably good care. Doing that, however, will require significant changes in financing, and especially in Medicare payment policy.

Issues for Further Consideration

1. How can we make sure that everyone receives the best possible care at the end of life?
2. Which organizations in the community need to collaborate to improve end-of-life care? What are some possible obstacles to overcome?
3. How can current public policy for end-of-life care be improved? What are some of the major issues that need to be addressed?
4. Why do some people choose to become volunteers? Why might volunteering be personally gratifying?
5. What kind of care would you want for yourself when you are dying? For your loved ones? What resources would you need in order to have this level of care?

Spiritual Care

by Christina M. Puchalski, M.D.

Spirituality is often the way dying people give meaning to their suffering. This was brought home to me by Sheila, a patient of mine who died of sickle-cell disease. As she faced the uncertainty of her life's ending, she prayed and meditated, asking her family and me not to just focus on her physical needs but to listen to her inner self.

Spirituality, defined as that which gives meaning to one's life, is often expressed in religious terms but can also be found in nature, music, art, family, and friendship. It can bring wholeness to the emotional, the physical and the intellectual parts of life. The spirit is the essence of the person—what makes them unique.

As people are dealing with illness and dying, they often cope with questions about meaning and purpose. Why did this happen to me? Why now? Dying can be an opportunity to find meaning in life by struggling through these questions. But that struggle can result in spiritual distress, and needs to be supported by physicians, nurses, social workers, families, and friends.

One can recognize spiritual distress by listening to the patient carefully as he or she struggles with doubt, uncertainty, and sadness. We cannot answer patients' questions, but we can support them as they work out answers for themselves. The aim is to help people make the transition from despair to peacefulness. Religious practice, meditation, guided imagery, journal writing, music, and art can all be spiritual resources. One can know which resources to use by listening to the patient. If music was comforting in the past then it may be appropriate now.

Caregivers often find it difficult to raise spiritual issues with their patients and loved ones. The essence of a spiritual history is listening to the patient's beliefs, fears, dreams, and struggles. It involves being truly present with all of one's attention and spirit. This can be done by any member of a patient's care circle. Healthcare providers can take a spiritual history during an intake history and physical, in the social-history section. Family and friends can make it part of routine conversation. I developed a tool for taking a spiritual history called FICA.



F Faith of Beliefs
I Importance and Influence
C Community
A Address

- F** Do you have faith and consider yourself spiritual or religious? What spiritual beliefs help you cope with this illness or with difficult times?
- I** What influence do your beliefs have on how you take care of yourself? How important are they in your life? How do they influence you in the way you make decisions about care at the end of life? Sometimes a person's spiritual beliefs may not be helpful at this time. A chaplain is trained to help people work with their beliefs to help them cope.
- C** Do you belong to a spiritual or religious community?
- A** How would you like me to address these issues in your care? (Referrals to chaplains or other spiritual directors may be essential and useful.)

The most important part of the spiritual history is that it provides a unique opportunity to bond with the patient on a very special, intimate level. Serving others and caring for them can be profoundly spiritual.

Those who are privileged to care for people while they are dying, be they our patients or our loved ones, can bring hope and comfort to them as they complete their lives. We need to ensure that our society and our systems of care preserve and enhance the dignity of all people, especially when they are made vulnerable by illness and suffering. In the end we need to go back to what Sheila asked me: "I am dying, are you listening?" We all need to listen to the dying and be with them, for them. The process of dying can be a meaningful one; one that we can all embrace and celebrate rather than fear and dread.

POST TEST ANSWERS

“On Our Own Terms” Moyers on Dying

Program 1: Living with Dying

1. Reaffirming relationships that have given one's life meaning.
 2. Before: Be there
Listen more than talk
Sensitively ask about plans
Offer help repeatedly
 - During: Be there
Touch and talk
Allow time alone
 - After: Be there
Assist with arrangements
Walk family to the care
Be there long term
3. An interdisciplinary program of care that provides symptom relief as well as emotional and spiritual support to terminally ill people and their families and friends.

Program 2: A Different Kind of Care

1. Palliative care is comprehensive care for people with life threatening illness. Hospice is one form of palliative care which requires a doctor to certify that a patient has a life expectancy of six months or less. Palliative care seeks to serve people earlier in the course of illness.
2. Emotional, spiritual and psychological distress can exacerbate pain.
3. Chiropractic medicine, homeopathy, meditation, nutritional therapy, acupuncture, massage and music therapy.

Program 3: A Death of One's Own

1. Compassionate care for the dying should begin with a commitment to keeping patients as comfortable and alert as possible. When good hospice care is available, fewer patients request assistance in hastening their deaths.
2. A proxy is someone who has the authority to speak on behalf of the patient when he or she is too sick to do so. **(Note: In Minnesota law the proxy is referred to as the health care agent.)**
3. An advance directive is a written document that states what you would want to happen given your medical condition. **(Note: In Minnesota law an advance directive is referred to as a health care directive.)**

Program 4: A Time to Change

1. Inappropriate and unwanted care, inadequate coverage for services, inadequate symptom management
2. Grief is a reaction to loss. It can be manifested in a variety of ways including intense feelings of sadness, guilt, anger or loneliness. It may also affect people physically, cognitively and spiritually resulting in aches and pains, forgetfulness, an inability to concentrate and struggles with faith and the meaning of life.
3. The essence of a spiritual history is listening to a person's beliefs, fears, dreams and struggles. Sample questions include: What spiritual beliefs help you cope with your illness? What influence do your beliefs have on how you make decisions about care at this stage of your illness? How would you like me to address any of these issues in your care? Do you belong to a religious community?