

The Michigan Physician Guide to

# END-OF-LIFE *Care*



Presented by



# The Michigan Physician Guide to End-of-Life Care

## Introduction

### Finding Comfort and Peace at the End of Life

This booklet was created to help physicians, patients and families — family in the broadest sense — deal more effectively with dying and death. Physicians can help their terminally ill patients and family members find comfort and peace at the end of life by studying this guide and reviewing the many websites and other resources listed at the end of each chapter.

Patients and families can use the information tailored specifically for them on the “For My Patients” pages related to the chapter topic and located at the end of each chapter. This information will help them plan how to live life to the fullest, take control of the dying process and find more comfort and peace during difficult times.

This booklet is filled with many medically concise how-to instructions. But softer words also are critically important when discussing and dealing with the end of life.

Dignity was the word used most frequently by the many contributors to this booklet. Comfort and caring, compassion and communication were heard often, as were respect and reassurance. Attention and active listening were emphasized, as well as spirituality and support.

We hope this booklet provides a new focus on dying and death and is a useful resource for you and your patients. It was originally produced in 2001 with a grant from the Michigan Department of Community Health and additional support from American Physicians. This updated guide has additional funding from Blue Cross Blue Shield of Michigan and the Michigan State Medical Society Foundation.

For additional information about many health-related issues such as aging or long term care, visit the Michigan Department of Community Health website at [www.michigan.gov/mdch](http://www.michigan.gov/mdch) and search under the Michigan Circle of Life or the End-of-Life Commission.

Information in this booklet regarding various Michigan laws is not intended to constitute legal advice. If you have a legal question, please contact an attorney.



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# END-OF-LIFE *Care*



## *Chapter 1*

Communication at the End of Life



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## Chapter 1: Communication at the End of Life

### Leading the Way in End-of-Life Discussions

**G**ood communication among physicians, patients and their family members is the cornerstone of providing appropriate end-of-life care for patients. Good communication also helps with healthy grieving for family members and physicians. End-of-life communication with patients may be difficult at first, but it is crucial.

Getting started simply amounts to facing up to what is happening. Physicians know their patients' diagnoses and prognoses, and the potential effectiveness (or ineffectiveness) of therapies. Patients know how they feel and are aware of their response to treatment. Family members note the effects of illness on their loved one.

It is like the elephant in the living room everyone might prefer to ignore. Getting started with end-of-life communication means dealing with the elephant.

Physicians should lead the way. The most important message physicians can give their patients and families is the assurance they will not be abandoned. The patient and family can then focus on peace and comfort while preparing for death. To effectively consider possible therapy options, patients need accurate, appropriate and timely information about the risks, benefits and burdens of possible therapies. They also need to know what might be expected as death approaches.

### Communicate as a Team

Dying is best faced as a team: patient, family, physician and other health care providers. Each team member has unique responsibilities. One role of the physician is to provide adequate and timely information for making treatment decisions. Family members can help loved ones consider the benefits and burdens of treatment options and be allowed to share their concerns.

It is generally accepted that dying patients and their families find satisfaction in activities that provide a feeling of life completion. Research has shown that dying patients often are able to live more fully during this important time of life when they can focus on what is truly important to them. Control of pain and other symptoms is essential. Personal preparation may include making peace with oneself, with others and according to one's spiritual beliefs. It also includes addressing old personal and interpersonal issues and disagreements; and giving and receiving forgiveness and blessings.



### Discussing End-of-Life Issues

To have a fruitful discussion about end-of-life issues with patients and families, consider the following:

- ♦ Set aside a time and place where the conversation can be held without interruptions.
- ♦ Include family members, if the patient desires.
- ♦ Encourage the presence of a caring support person whenever possible.
- ♦ Provide educational materials about suggested procedures and treatments.
- ♦ Discuss advance directives such as the durable power of attorney for health care.
- ♦ Discuss treatment options including palliative or hospice care, as appropriate.
- ♦ Ask the patient what he or she needs and in what priority.
- ♦ Let your patient know you will help achieve his or her end-of-life goals.

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Lastly, each team member—including the physician—needs to prepare for a healthful mourning period following a loved one’s death. When a physician suppresses the natural grieving process after losing a patient it may lead to emotional withdrawal from issues of care. This can affect relationships and self-image, and may contribute to professional burnout.

## General Principles of End-of-Life Communication

Feeling and expressing emotions of love, fear, anger and sadness are normal and inescapable parts of end-of-life communication. They may be experienced alone or in various combinations. The inter-disciplinary care team—including the patient, family, physician and other care providers—needs to recognize and accept that they all will be feeling these emotions and prepare to deal with them compassionately.

Medical information and the manner in which it is delivered can both help and harm patients and families. Physicians should try to determine what information patients and families want to hear and need to know. Sensitively ask how, when and to whom information about the patient’s condition should be addressed. Sometimes, when more support is available, additional information will be better received.

Patients and families need information that can be understood, without technical terms, medical jargon or euphemisms. Before talking with patients and families, it may be helpful if physicians rehearse what they want to say, without using medical terms. It is also important to occasionally stop during the conversation and ask whether patients and families comprehend the explanations, or have additional topics they want to discuss.

Usually, patients and families intuitively know when the end of life is approaching. Rather than attempting to absorb more than they are ready to consider and use, it is a good idea to hold several meetings with the patient and family. Meetings can be spaced according to decisions that need to be made and the next one planned at the end of each meeting to avoid feelings of abandonment.

It is important that the patient or any family member feel welcome and comfortable requesting a meeting with the physician to discuss impending personal or medical decisions. Early on, it is valuable to reassess the patient’s and family’s understandings of what

questions are being raised and what new or additional information will be needed.

These meetings can be sacred events, with time for appropriate silence, non-verbal spiritual connectedness, meditation or silent prayer. They provide an opportunity to share emotions, laughter and tears. Traditionally, these have been difficult times for many physicians.

## Communicating Prognosis

Patients have differing goals in mind when discussing their prognoses. Some want a sense of their future so they can plan accordingly. Others want reassurance that things are not so serious or hopeless.

When attempting to communicate prognosis:

- ♦ Be honest. If you don’t know, say so.
- ♦ Use averages. (*“One third of people will do well a year from now, half will live about six months. However, you are unique and I don’t know exactly what course this disease will take for you.”*)
- ♦ Emphasize the limits of predictions. (*“What this will mean for you as an individual no one can be really sure. We can’t predict surprises and should plan in case something serious happens.”*)
- ♦ Reassure the patient you will continue to care for him or her, whatever happens.
- ♦ Caution patients and their families that unexpected events can happen. Suggest that they get their affairs in order so they won’t be so vulnerable if something unexpected does happen. Use language such as *“What if...”* or *“Let’s hope for the best and prepare for the worst.”*
- ♦ Never tell a patient *“There’s nothing more that can be done,”* or *“Do you want everything done?”* Talk instead about the life yet to be lived, and what can be done to make it better (and what might make it worse).
- ♦ Sensitively bring up the important subject of advance care planning, as outlined in the next chapter.

## When the Dying Patient is a Child

One of the most difficult responsibilities any health care provider encounters is caring for a dying child and the child’s family, including siblings. Communicating well with the family and child is particularly crucial, yet may be difficult at first.

Children represent our hopes and dreams for the future, so when a child faces a terminal illness, a normal

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reaction of both providers and parents may be to fight for a cure to the very end, all the while knowing the odds of success may be minimal. Appropriate palliative care should be offered throughout the disease continuum, from diagnosis to bereavement. It is important to remember that each end-of-life care decision by the patient, family and care providers is crucial to the child's experience.

A comprehensive website was developed by the Texas Children's Cancer Center at the Texas Children's Hospital in Houston; [www.childendoflifecare.org](http://www.childendoflifecare.org). This web site offers:

- ♦ advice about communicating effectively with families
- ♦ information about bridging the transition from aggressive treatment to quality palliative care

- ♦ an outline of physical care requirements of children
- ♦ suggestions on how to offer supportive care for the family including spiritual, religious and cultural issues
- ♦ a support section for health care professionals' own emotions.

Childrens' continuing physical, emotional and cognitive development sets them apart from adults. This influences all aspects of their care, including medications, their understanding of their disease, their communication skills and their level of dependence.

The main caregivers for children are usually parents, with care frequently taking place at home. Parents and siblings will need support throughout the child's illness and their bereavement.

## Making Promises to Patients

When you talk with patients who have advanced stages of serious illness, what do you promise them? Symptom relief? Ongoing support? Telephone access to you? All are important to these patients. Physicians might want to take on the challenge posed by Joanne Lynn, MD, who urges doctors and others to make seven promises. Dr. Lynn is the founder of Americans for Better Care of the Dying (ABCD) and was the principal investigator for the SUPPORT study that described experiences of almost 10,000 patients near the end of life and motivated national calls for reform.

ABCD suggests that the next time you meet with a very sick patient and his or her family, try making at least two or three of these seven promises to them:

- ♦ You will receive the best of medical treatment.
- ♦ We will keep you free from overwhelming pain and other symptoms.
- ♦ You will have continuous, comprehensive and coordinated care.
- ♦ We will prepare you for everything that is likely to happen in the course of the illness.
- ♦ Whenever possible, I will seek out and respect your wishes.
- ♦ We will take into account your financial, emotional and practical resources, as well as those of your loved ones.
- ♦ We will help you to make the best of every day.

Patients and families need to be able to rely upon their local health care resources, and physicians need to work with others so it is possible to make and keep these promises.

See details about using the seven promises and suggestions for improving care for the dying at [www.abcd-caring.org](http://www.abcd-caring.org). Refer patients to "The Handbook for Mortals" by Dr. Lynn and take a look at "Improving Care for the End of Life, A Sourcebook for Clinicians and Health Care Managers." Excerpts from both can be read at the ABCD's web site. Full text of the first and excerpts from the second can be read online at the ABCD web site.

## Six Steps to Communicating Bad News

Robert Buckman, MD, an oncologist specializing in communication issues, strongly urges physicians to take personal responsibility for the important task of communicating bad news and recommends the following steps be taken.

### 1. Getting started.

- ♦ Plan what will be discussed.
- ♦ Confirm medical facts.
- ♦ Create an environment conducive to dialogue.
- ♦ Allow adequate time and prevent interruptions.
- ♦ Determine whom the patient would like present.

### 2. What does the patient know?

- ♦ Establish what the patient knows.
- ♦ Assess ability to comprehend bad news.
- ♦ Reschedule if unprepared.

### 3. How much does the patient want to know?

Recognize that people handle information differently, depending on their educational level, ethnicity, culture, religion, socioeconomic status, age and developmental level. Ask the patient and family how they would like to receive information. If the patient prefers not to receive critical information, establish to whom information should be given.

Possible questions might include:

- ♦ *“If this condition turns out to be something serious, how much do you want to know?”*
- ♦ *“Would you like me to tell you the full details of your condition?”*
- ♦ *“With whom should I talk about these issues?”*

### 4. Sharing the information.

Deliver the information in a sensitive and straightforward way. Avoid talking in a monologue—instead promote dialogue. Avoid jargon and euphemisms. Say the bad news and stop. Silence is a powerful and effective communication tool. Pause between bits of information to check for understanding. Do not minimize the severity of the situation, as it may lead to misunderstanding of your message.

Here is some language that might help in breaking the bad news:

- ♦ *“I’m afraid the news is not good. The biopsy showed that you have colon cancer.”*

- ♦ *“The report is back, and it’s not as we had hoped. It showed cancer in your colon.”*

### 5. Responding to family and patients’ feelings.

Patients and families will respond to bad news in a variety of ways. Some respond with tears, anger, sadness and other strong emotions. Others display immediate feelings of guilt, disbelief or shame. Some may try to intellectualize the information. A few may exhibit fight or flight tendencies and may bolt from the room or totally withdraw within themselves.

After the patient and family have had time to react, support them through the broad range of reactions. Listen quietly and attentively, acknowledging their emotions. Help them to identify their feelings, then express empathy. Use language such as:

- ♦ *“I imagine this is difficult news...”*
- ♦ *“Tell me more about how you are feeling about what I just said.”*
- ♦ *“What worries you most?”*
- ♦ *“I wish the news were different.”*
- ♦ *“Is there anyone you would like me to call?”*

### 6. Planning and follow-up.

- ♦ Plan for next steps (additional information, tests, treatment of symptoms, referrals) as needed.
- ♦ Discuss potential sources of support.
- ♦ Give contact information, set next appointment.
- ♦ Before leaving, assess the safety of the patient and the supports that exist at home.
- ♦ Repeat news at future visits.

**Note:** If there is a language barrier, enlist the assistance of an experienced translator who understands medical terminology and is comfortable conveying bad news. Avoid using family members as primary translators whenever possible.

Adapted from *How to Break Bad News: A Guide for Health Care Professionals*, by Robert Buckman, MD. Reprinted with permission.

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## Resources

### “Bad News” References

- ♦ Buckman R.; *How to Break Bad News: A Guide for Health Care Professionals*. Baltimore: Johns Hopkins University Press, 1992.
- ♦ Ngo-Metzger, Q; August KJ; Srinivasan M; Liao S; Meyskens FL Jr. *End-of-Life Care: Guidelines for Patient-Centered Communication*. Am Fam Physician. 2008 Jan 15;77(2):167-74.
- ♦ Wittenberg-Lyles EM; Goldsmith J; Sanchez-Reilly S; Ragan SL *Communicating a Terminal Prognosis in a Palliative Care Setting: Deficiencies in Current Communication Training Protocols*. Soc Sci Med. 2008; 66(11):2356-65.

### Communication References

- ♦ **www.abcd-caring.com**—Americans for Better Care of the Dying (ABCD). A website dedicated to social, professional and policy reform aimed at improving the care system for patients with serious illness and for their families.
- ♦ **www.completingalife.msu.edu**—Completing a Life. A website inviting patients and families to learn about the practical, emotional, spiritual and medical issues faced by those dealing with advanced illness.
- ♦ Nathan E. Goldstein; Anthony L. Back; R. Sean Morrison. *Titrating Guidance: A Model to Guide Physicians in Assisting Patients and Family Members Who Are Facing Complex Decisions*. Arch Intern Med, Sep 2008; 168: 1733 - 1739.
- ♦ Steven Z. Pantilat. *Communicating With Seriously Ill Patients: Better Words to Say*. JAMA, March 25, 2009; 301: 1279 - 1281.
- ♦ Michael W. Rabow; Joshua M. Hauser; Jocelia Adams. *Supporting Family Caregivers at the End of Life: “They Don’t Know What They Don’t Know”* JAMA, January 28, 2004; 291: 483 - 491.

### Care of Children References

- ♦ **www.childendoflifecare.org**—Texas Children’s Hospital, Texas Children’s Cancer Center. A website offering a comprehensive site about “End-of-Life Care for Children” and the differences encountered when the dying patient is a child.
- ♦ Himmelstein, BP; Hilden, JM; Boldt, AM; Weissman, D. *Pediatric Palliative Care*. N. Engl J Med 350:1752, April 22, 2004.
- ♦ Liben, S; Papadatou, D; Wolfe, J. *Paediatric Palliative Care: Challenges and Emerging Ideas*. Lancet. 2008 Mar 8;371(9615):852-64.



## FOR MY PATIENTS

### End-of-Life Care: Talking About End-of-Life Issues

#### Communicating with Others at the End of Life

Sometimes it is emotionally difficult for family and friends to talk about the future of a loved one who wants to discuss their own wishes as they approach the end of life. It's not easy for anyone, but the benefits are great for all involved when there is open and honest communication. Following are some suggestions for getting started.

##### **Talk about a situation someone else experienced.**

One way to begin talking about your wishes is to share a story about friends or relatives who faced a difficult situation. You might say something like: "Do you remember what happened to so and so and what their family went through? I don't want that to happen to me. That's why we need to talk about this now."

##### **Point out the possible consequences of not talking.**

Someone may be more willing to talk openly with you if you start by saying: "If we don't talk about this now, we could both end up in a situation that is even more uncomfortable. I'd really hate for that to happen."

##### **Write a letter, or make an audio tape or video recording.**

It may help you and others understand your desires more clearly if you write them down or make a recording. After they read your letter, hear your tape or watch your video, it may be easier for them to talk with you.

##### **Who should you talk to?**

Think about the people who are important to you. If you were seriously ill or unable to communicate, who would you want around at this time? It might include family, close friends, clergy, health care providers or caregivers.

##### **What if you don't have close family or friends?**

Your best option is to write down your wishes, either as a formal advance directive or personalized statement, or both. Ask your physician for an advance directive form. In addition, you might make an audio or video recording, and share it with your health care providers.

Adapted from the advance care planning workbook, "Your Life, Your Choices" and from the website [www.completingalife.msu.edu](http://www.completingalife.msu.edu). Reprinted with permission.



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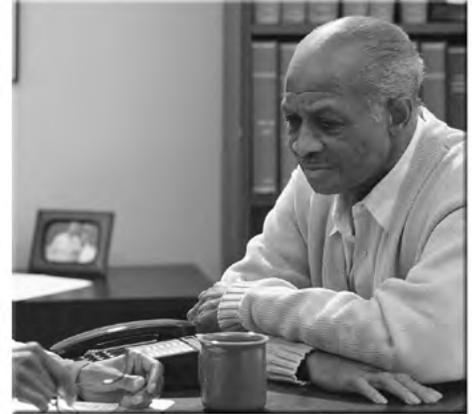
## *Chapter 2* Advance Care Planning



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## Chapter 2: Advance Care Planning

### Discussing Advance Directives with Your Patients



Advance care planning allows patients to indicate how they want to be treated if they become seriously ill. It helps families and physicians make decisions when patients are unable to do so themselves.

Time spent on advance care planning may become crucial if a patient becomes unable to make his or her own decisions or state his or her wishes concerning health care. Physician involvement in advance care planning builds trust. It also increases professional satisfaction that comes from acting in a patient's best interest and reduces stress involved when caring for a patient who is dying.

Surveys show only 10 to 25 percent of Americans have documented their end-of-life choices or appointed a patient advocate. It is important to routinely introduce the topic of advance care planning to all patients, regardless of their age or current health.

#### Michigan's Durable Power of Attorney for Health Care

In general, an advance directive is a written advance care planning document that specifies how medical decisions should be made for a patient who is unable to make or express his or her wishes concerning health care.

Specifically, the durable power of attorney for health care (DPAHC) is the form of advance directive recognized by statute in Michigan (1998, Public Act 386).

To conform to Michigan law, a DPAHC must be signed by the patient, dated and witnessed. The patient designates someone, such as a relative or other person, as a patient advocate to make specified health care decisions for the patient if the patient is unable to do so, such as approving surgeries or medications, or even withholding or withdrawing treatment, if so specified in the patient's DPAHC document.

The designation of a patient advocate must be voluntary, in writing and witnessed by two people who are not the patient's spouse, relative, heir, physician, patient advocate, employee of the patient's life insurance or health insurance provider, or employee of the health facility treating the patient. The witness cannot sign

unless the patient appears to be of sound mind and under no duress, fraud or undue influence. A completed DPAHC copy should be placed into the patient's medical record file. Sometimes it can be difficult to find qualified witnesses, especially when in health care settings, so patients should be encouraged to complete a DPAHC as early as possible.

It is a good idea for patients to state in writing on the DPAHC form their general preferences regarding health care. For example, a person might state when medical technology should be used, and whether the patient advocate has the authority to withhold or withdraw medical care that may result in death.

#### How a Living Will is Different

A living will and a durable power of attorney for health care are both advance directives, but they are not the same things. A living will can be an unwitnessed written document through which a patient may state his or her wishes regarding various health care situations and treatments, including life-sustaining treatment.

There is no statutory law in Michigan that recognizes a living will. However, a living will might be used as evidence of the patient's wishes. Because there

is no Michigan law recognizing living wills, there is no special liability protection for a surrogate decision maker or physician who voluntarily chooses to follow a patient's wishes as stated in a living will.

## When a Durable Power of Attorney for Health Care Applies

A patient may authorize the patient advocate to make specified medical treatment decisions for the patient when the patient has been determined by the patient's physician and another physician or licensed psychologist to be unable to make or communicate such decisions.

A decision by the patient advocate to withhold or withdraw life-sustaining treatment from the patient may be made only if the patient has clearly and convincingly authorized such a decision, preferably in writing, and the patient has acknowledged that such a decision may allow his or her death.

## No Greater Liability Exposure for Physicians

The Michigan DPAHC law states that a person providing, performing, withholding or withdrawing care, custody or medical treatment as a result of the decision of an individual who is reasonably believed to be a patient advocate and who is reasonably believed to be acting within the authority granted by the designation is liable in the same manner and to the same extent as if the patient had made the decision on his or her behalf.

## Introducing the Topic of Advance Care Planning to Your Patients

Research shows that patients expect physicians to introduce the topic of advance care planning. The following steps should help ease the discussion:

1. Make it a routine process with every adult patient in your practice.
2. If your patient already has advance directive documents, ask to review the material and suggest any appropriate changes. Make a copy to place in the patient's record.
3. Explain the process. Discuss the durable power of attorney for health care and Designation of Patient Advocate Form (available from the Michigan State Medical Society at 517- 337-1351) and have forms readily available. See other resources listed on the "For My Patients" page.

## Discussing Organ and Tissue Donation

Organ and tissue donation saves and improves lives. Still, some people have concerns about donation, so it is important to approach the topic with patients carefully and thoughtfully. The following are general suggestions:

- ♦ Approach the topic of organ donation with patients carefully and thoughtfully. If you are a registered organ donor, mention it to your patient when discussing the topic.
- ♦ Build organ donation options into your standard patient information forms, records or surveys. Choose a non-crisis visit to discuss the subject, if possible. Patients are more likely to consider donation when they are healthy, calm and not distracted. (If a patient has been severely injured or even declared brain dead, collaborate with Gift of Life Michigan BEFORE approaching the patient's family about donation; not doing so is a violation of CMS rules.)
- ♦ Emphasize the positives. A single organ and tissue donor can save up to eight lives and improve the lives of 50 others. Everyone is a potential donor; there is no age limit and very few specific health conditions that rule out joining the Michigan Organ Donor Registry.
- ♦ Rebut the myths:
  - Explain that donation doesn't cost the family of a donor anything.
  - Any type of funeral arrangement is possible after donation, including a viewing.
  - The transplant team is completely separate from the doctors and other medical personnel who are trying to save the potential donor's life.

Have donor registry brochures and other information available. Call Gift of Life Michigan at 1-800-482-4881. Direct patients to online registry at [www.giftoflifemichigan.org](http://www.giftoflifemichigan.org).

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## Michigan's Do-Not-Resuscitate (DNR) Procedure Act

The Michigan Do-Not-Resuscitate (DNR) Procedure Act (1996 PA 193) is another advance directive option. In general, this directive requires that emergency personnel honor the health care wishes of the patient.

This law allows an adult patient or the patient advocate of an adult patient to complete a DNR order directing that no resuscitation be initiated if the patient arrests in a setting outside of a health care facility or institution.

The act gives a patient two ways to communicate with emergency personnel. The patient may wear a "Do-Not-Resuscitate" identification bracelet and the patient may have a copy of a DNR order readily available. After a health professional determines that the patient has no pulse or evidence of respiration, the patient may not be resuscitated if the patient is wearing the bracelet, or if the health professional is given a Do-Not-Resuscitate order. DNR bracelets are available by calling the Michigan Hospice and Palliative Care Organization at 1-800-536-6300.

4. If your patient does not seem comfortable with the topic of advance directives, provide the information and be supportive, but do not push the conversation unless some medical urgency exists.
5. Suggest that your patient discuss with family members or friends how care should be managed if the patient can no longer make those decisions.

## Reviewing Your Patient's Wishes

Once a patient has made decisions about his or her future care planning, it is important for the physician, patient and patient advocate to review the patient's wishes. This is your opportunity to correct inconsistencies or clear up misunderstandings.

After a durable power of attorney for health care form has been reviewed and accepted by the appointed patient advocate(s), the patient should give you a copy of the signed document to place in the patient's medical record file. Encourage your patient to keep duplicates and the original signed document with other important papers and give copies to the patient advocate and family members. Forms provided by the Michigan State Medical Society include a wallet card on which the patient may list the patient advocate(s) and telephone number(s). If the patient is being treated at a health care facility, a copy of the document should be filed there as well.

Assure your patients that their wishes will be honored if they become unable to make or communicate their own decisions, and that they will be kept as comfortable and pain free as possible. See the next chapter, "Pain and Other Physical Symptoms."

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## Advance Directive Resources

### Websites

- ♦ [www.agingwithdignity.org/five-wishes.php](http://www.agingwithdignity.org/five-wishes.php)—Aging With Dignity offers information about ordering an advance care document called “Five Wishes.”
- ♦ [www.giftoflifemichigan.org](http://www.giftoflifemichigan.org)—Gift of Life Michigan is a full service organ recovery organization that acts as the intermediary between donors, physicians and hospital staff, and provides all services necessary for organ and tissue donation and transplantation.
- ♦ [www.msms.org/dpa](http://www.msms.org/dpa)—Michigan State Medical Society offers information for ordering Durable Power of Attorney for Health Care forms. Or call MSMS at 517-337-1351 to order forms.
- ♦ [www.partnershipforcaring.org](http://www.partnershipforcaring.org)—Partnership for Caring: America’s Voices for the Dying is a national non-profit organization devoted to raising consumer expectations and demand for excellent end-of-life care. Offers advance directive information that is state-specific.

### Books/Articles

- ♦ Crane MK; Wittink M; Doukas DJ. *Respecting End-of-Life Treatment Preferences. American Family Physician.* 2005 Oct 1;72(7):1263-8.
- ♦ James A. Tulsky. *Beyond Advance Directives: Importance of Communication Skills at the End of Life.* JAMA, July 20, 2005; 294: 359 - 365.
- ♦ S. H. Wanzer and J. Glenmullen. *To Die Well: Your Right to Comfort, Calm, and Choice in the Last Days of Life.* Cambridge, MA, Da Capo Press, 2007.

### End-of-Life Care: Advance Care Planning

## Facts About a Durable Power of Attorney for Health Care

Taking the time now to complete a Durable Power of Attorney for Health Care form can save your loved ones from future confusion and anxiety if you ever become unable to communicate your own wishes regarding medical care. Please review the facts below and then obtain a form from one of the sources listed on the opposite side of this page.

### According to Michigan law:

1. Anyone who is age 18 or older, and of sound mind, may and should have a durable power of attorney for health care in case something happens and you can't make decisions for yourself. You can do this by completing a Durable Power of Attorney for Health Care form.
2. Michigan's Patient Advocate Act allows you to appoint a relative or other person as your patient advocate to make medical treatment decisions for you if you are unable to do so yourself. You also may appoint a successor patient advocate in case your first choice is unavailable or becomes unwilling or unable to speak for you.
3. You may change the person you appoint as your patient advocate at any time and by any means of communication.
4. You may write on the form the types of treatment you do and do not want, including whether or not you want heroic measures such as a breathing machine to help you breathe, or feeding by tubes if you cannot eat and drink by yourself. You should discuss your wishes in detail with the person you have chosen as your patient advocate.
5. If you write on your form that you want your patient advocate to order doctors to withhold or withdraw life-sustaining treatment in certain situations, your wishes must be honored by the doctors. The only exception is in the case of a pregnant woman where doing so would directly result in her death and the death of her fetus.
6. A durable power of attorney for health care is different from a living will. A living will is a written document that you fill out, indicating your choices about various treatment options. If you have a living will, many experts believe you also should appoint a patient advocate using a Michigan Durable Power of Attorney for Health Care form. Your patient advocate then will have the right to enforce your choices as written on your living will.
7. You should give a copy of your durable power of attorney for health care form to your doctor, to your local hospital and to your patient advocate(s). You should keep an original copy with your other important papers. You might keep a copy in your purse or the name and telephone number of your patient advocate in your wallet.

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## Where to Get Durable Power of Attorney for Health Care Forms

1. Most local hospitals have these forms available at no charge at their patient registration areas.
2. Your family attorney may help you complete a Durable Power of Attorney for Health Care form.
3. Local legislators often have these forms available at no charge for people in the area they serve.
4. Contact the Michigan State Medical Society at 517-337-1351 and order two Michigan-specific officially endorsed Designation of Patient Advocate Forms for \$2. Or visit its web site at **[www.msms.org/dpa](http://www.msms.org/dpa)** to obtain information about ordering these forms by mail. This simple Designation of Patient Advocate Form can be completed by you at no additional cost.
5. Get advance directives by using the website “Completing a Life” at **[www.completingalife.msu.edu](http://www.completingalife.msu.edu)**.
6. Learn more about advance directives in the “Five Wishes” model at **[www.agingwithdignity.org/five-wishes.php](http://www.agingwithdignity.org/five-wishes.php)**.

## FOR MY PATIENTS

### End-of-Life Care: Sharing Your Advance Care Plan

#### Important Issues to Discuss

Below are nine important issues to discuss with family, loved ones and health care providers as you make end-of-life decisions. Talking about these issues may be difficult, but it will help your loved ones decide what to do if you are not able to make these decisions yourself.

**Your Choice of a Spokesperson.** If you have designated a patient advocate or a spokesperson to express your wishes, make sure your loved ones and health care providers know who that person is, how to contact them and why you made that person your patient advocate.

**Your Beliefs and Values.** Talk about what makes life worth living to you, what would make it unbearable, and why.

**Health Conditions.** Explain how you feel about being kept alive if you are not able to speak for yourself.

**Life-prolonging Treatments.** How do you feel about life-prolonging treatments? Do you want them?

**Your Vision of Dying.** If you hope to die in a certain way—at home, in your sleep, free from pain—talk about it.

**Organ and Tissue Donation.** Discuss your wishes with family members. To register as an organ and tissue donor, go to [www.giftoflifemichigan.org](http://www.giftoflifemichigan.org).

**Funeral Arrangements.** Share your thoughts about the type of service you would like to have and what you want to have done with your remains.

**Documentation of Your Wishes.** If you have completed an advance directive or other similar statement, make copies for your physician, your patient advocate, family members, friends and health care institutions. Carry with you the name and telephone number of your patient advocate.

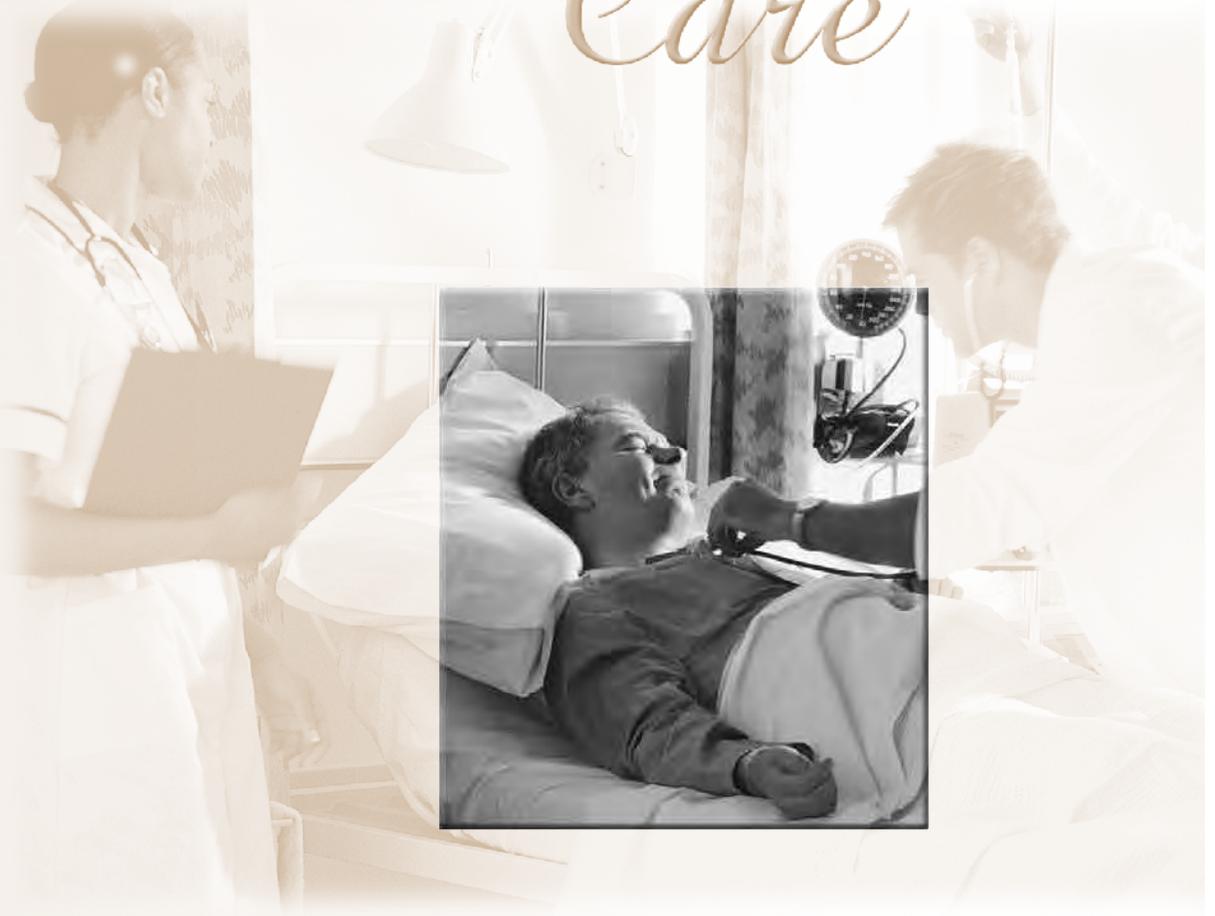
**How Others Should Use Your Advance Directive.** Your instructions and personal statements can be understood either as specific instructions or general guidelines. You can help others interpret your wishes by including something like this in your document:

- ♦ *“I would like the statements in my advance directive followed to the letter.”*
- ♦ *“I would like the statements in my advance directive to be used as a general guide.”*
- ♦ *“I want those statements that I have marked with a star (\*) followed to the letter because I feel very strongly about them. Use the rest of my statements as a general guide.”*

Adapted from the advance care planning workbook, “Your Life, Your Choices” and from the website [www.completingalife.msu.edu](http://www.completingalife.msu.edu). Reprinted with permission.



# END-OF-LIFE *Care*



## *Chapter 3*

Pain and Other Physical Symptoms

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## Chapter 3: Pain and Other Physical Symptoms

### Pain Is Known Best by the Person Experiencing It



Quite simply, “pain is what the patient says hurts,” according to Dame Cicely Saunders, MD, founder of the modern hospice movement. In other words, pain is known best, and only, by those experiencing it. Pain can be relieved in most terminally ill patients, and managed for the rest. Cancer pain guidelines available on the Michigan Cancer Pain Initiative website at [www.mipain.org](http://www.mipain.org) can be used for managing cancer pain as well as pain in other terminal illnesses. The guidelines include using opioids (narcotics) and other medications and include various medical treatments such as nerve blocks, surgery, radiation and chemotherapy. They also include complementary therapies such as massage, imagery and relaxation techniques. Support groups can be an additional source of comfort for terminally ill patients and their families.

#### Assessing Pain

For too long, too little attention has been paid to pain. Physicians and other health care professionals need to ask patients, especially those who are terminally ill, about their pain and level of comfort or discomfort. Continually reassessing a patient’s pain is crucial to successfully treating and effectively managing it.

National standards developed in 2000 and 2001 by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) require health care facilities to:

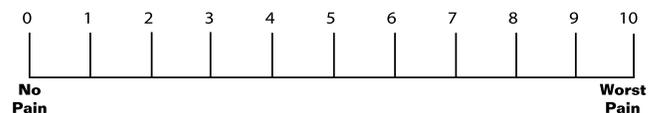
- ♦ recognize the right of patients to appropriate assessment and management of pain
- ♦ identify pain in patients during their initial assessment and reassessments
- ♦ document acceptable outcomes of treatment
- ♦ educate providers, patients and their families about pain management

Several dimensions of pain must be evaluated when gaining an understanding of a patient’s pain experience. The most important is severity or intensity. Patients can use a 0-10 scale to rate the severity of their pain, with 0 being no pain and 10 the most severe pain imaginable. Scales that use pictures of faces can help children or those with a language barrier communicate the severity

of pain. Pain scales also help evaluate success of pain treatment. Two examples are below.

#### Pain Scales

##### Numeric Pain Intensity Scale



##### Visual Analog Scale – Faces



#### Other Dimensions of Pain

In addition to the pain scales, ask your patients these questions to help assess their pain experience:

- ♦ Severity: Use pain scales.
- ♦ Quality: Is it dull, sharp, pressing, aching, burning, etc.?

- ♦ Location: Is it deep inside or close to the skin? Does it stay in one place or spread?
- ♦ Duration: When did it start? Has it changed or gotten worse? Is it steady or does it come and go? Is it better or worse at any time of the day or night?
- ♦ What brings it on? Makes it worse? Helps relieve it?
- ♦ Treatments: What has been used? How effective were those treatments? Were there side effects: nausea, itching, drowsiness?

Successful pain management requires evaluating and understanding the concept of “total pain,” as described by hospice pioneer Dame Cicely Saunders, MD. It requires evaluating the physical symptoms of pain, and then looking beyond them to the effects that pain has on the lives of people who experience it.

Successful pain management also requires knowing how each patient copes physically, psychologically and spiritually with his or her pain symptoms. Are emotional symptoms contributing to the individual’s pain? What about interpersonal problems? Is there spiritual or existential distress that needs attention? (See Chapter 7, “Emotions, Spirituality and the Task of Dying.”) Some of this information may be gained by simply asking direct questions, but some may require a more sophisticated assessment.

Understanding, acceptance and support by family members and the entire health care team are crucial to relieving and managing total pain.

Dimensions of total pain include:

- ♦ Physical pain: Medical intervention can help relieve physical pain.
- ♦ Emotional pain: Anxiety, fear, anger and depression are often part of the experience of pain. Medications may help, but addressing the emotions and their causes also is critical.
- ♦ Social pain: Social isolation, changes in relationships, tension and financial stress within families are sources of social pain.
- ♦ Spiritual pain: Not having made final peace with oneself, with others and with one’s faith can be a source of spiritual pain.

Many other medical interventions may be helpful for some patients, such as nerve blocks and radiation therapy. Physical therapy and occupational therapy may help with pain management and may also improve functional status.

Complementary therapies can play an important role in pain relief for many patients. Techniques like massage, relaxation, imagery, music and self-hypnosis can help relieve the stress and tension of terminal illness as well as assist with pain relief. People experiencing pain, along with their families, also may find comfort in support groups.

Addressing spiritual distress is another vitally important component of pain relief for many terminally ill patients. Strategies for understanding and addressing these concerns are discussed in Chapter 7, “Emotions, Spirituality and the Tasks of Dying.”

## Pain Relief

Opioid (narcotic) medications are the cornerstone of pain relief for patients facing terminal illnesses. Unfortunately, many myths about opioid use have stood in the way of appropriate therapy. Non-narcotic medications also play an important role in pain relief, from non-steroidal anti-inflammatory drugs (NSAIDs) to adjuvant analgesics such as corticosteroids, anticonvulsants and antidepressants.

### Barriers to Adequate Pain Management

**Despite our current knowledge and treatments, pain too often is inadequately managed. Barriers to good pain management can arise from patients and their families, from health care professionals and from the health care system itself. Barriers to adequate pain management may include:**

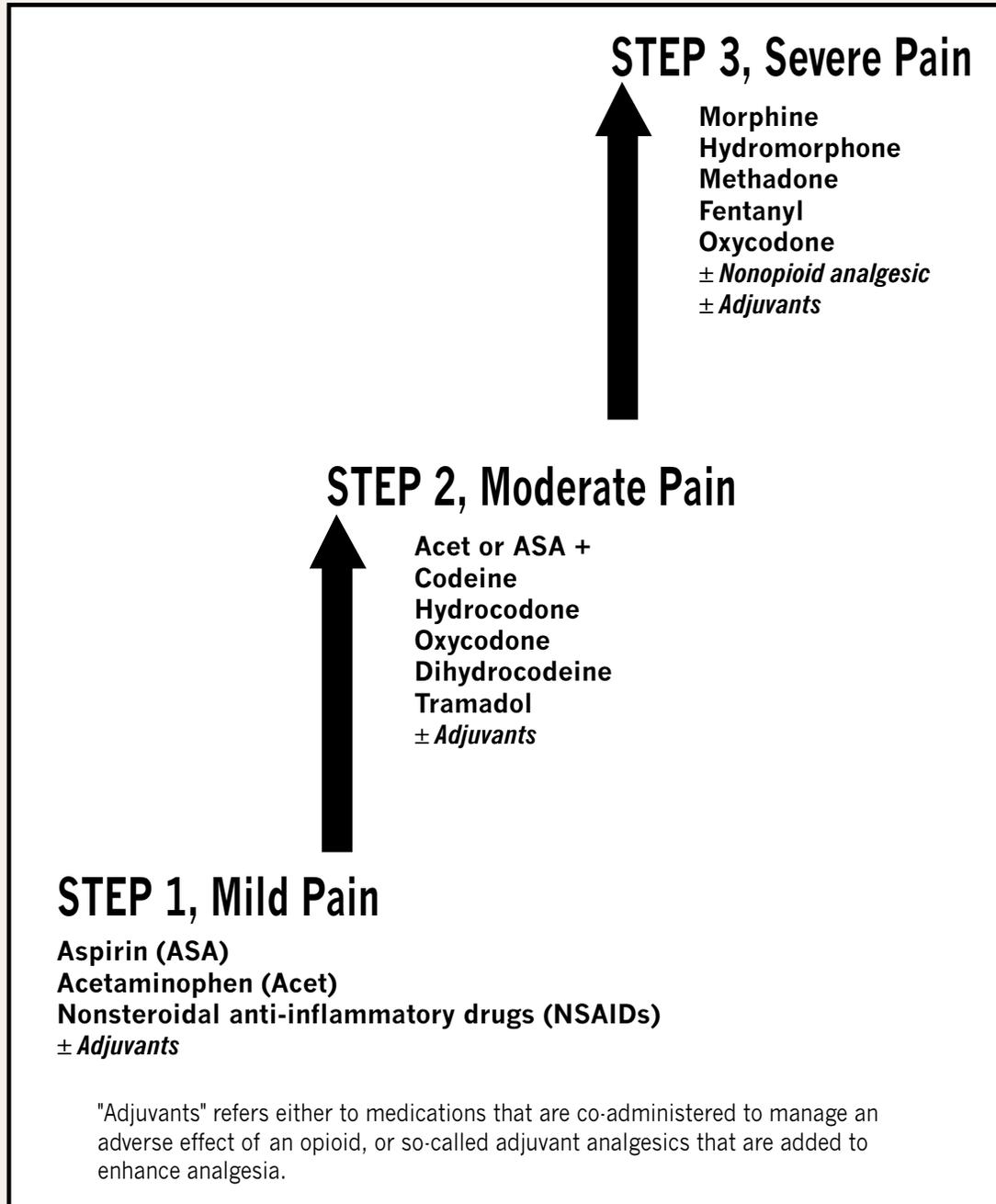
- ♦ **Insufficient emphasis on the importance of pain management.**
- ♦ **Failure to assess the physical, emotional, social and spiritual causes of pain.**
- ♦ **Inadequate knowledge of effective pain management treatments.**
- ♦ **Irrational fear of addiction, tolerance and physical dependence.**
- ♦ **Physicians’ fear of governmental regulations related to prescribing opioids (narcotics).**
- ♦ **Inadequate insurance coverage or access to medical care for some patients and families.**

In 1986, the World Health Organization (WHO) developed a three-step conceptual model to guide the management of cancer pain. It provides a simple, well-tested approach for the rational selection, administration and titration of analgesics. Today, there is worldwide

consensus favoring use of this model for the medical management of all pain associated with serious illness. The following chart is adapted from the WHO and Education for Physicians in End-of-life Care (EPEC) Project training materials.

## Pharmacological Approaches to Pain Management

Adapted from the Education for Physicians in End-of-life Care (EPEC) Project's Version of the World Health Organization's Three-Step Ladder for Management of Pain.



## Myths About the Use of Opioids (Narcotics) to Control Pain

**MYTH:** *Strong opioids (narcotics), such as morphine, should be used only when pain is unbearable or when death is near.*

**FACT:** If a patient's pain requires the use of strong opioids, they should be used immediately. In fact, this will help prevent changes to the nervous system that can make future pain more difficult to treat.

**MYTH:** *The use of opioids will hasten death.*

**FACT:** Appropriate use of opioid pain relievers does not shorten life. In fact, many experts agree that the physical stress of unrelieved pain may hasten death.

**MYTH:** *Strong opioids cause sedation and loss of function.*

**FACT:** Mild sedation may occur when opioids are first used, but with appropriate adjustments of dosage and schedule, most patients find they function very well—often better—than when in pain.

**MYTH:** *Strong opioids such as morphine can be provided only parenterally.*

**FACT:** Morphine and other opioids are very effective when taken orally. Fentanyl also may be administered transdermally, through a skin patch. These simpler routes of administration are usually less expensive, more convenient and just as effective.

**MYTH:** *Opioid use for pain relief causes drug addiction.*

**FACT:** True addiction (psychological dependence) is rare when opioids are used to relieve pain.

Many studies indicate less than one percent of patients with pain develop this problem from medical treatment. Physical dependence (withdrawal symptoms if medication is stopped abruptly) is common with sustained use of opioids and should be anticipated. It can be managed easily if the patient's opioid requirements decrease. Tolerance (need for increased dosage to maintain same effect) infrequently occurs. Need for increased dosage is more commonly due to disease progression. When tolerance does occur, opioids can simply be increased as needed.

**MYTH:** *Opioid medications should be used only when needed.*

**FACT:** Pain relievers are most effective when pain is kept under continuous control by scheduled doses. An as needed schedule (PRN) often leads to less effective relief and higher total use.

**MYTH:** *Side effects from opioids may prevent many patients from using them for pain relief.*

**FACT:** Side effects such as nausea and vomiting, constipation and sedation or confusion can be managed by skilled clinicians. Properly managed, side effects rarely interfere with a patient's ability to use opioids.

**MYTH:** *Opioid medications will relieve all pain.*

**FACT:** Certain types of pain, commonly bone and nerve pain, may not respond well to opioids. When a patient treated with opioids experiences persistent sedation without good pain relief, he or she may have opioid resistant pain. An expanded treatment plan that may include adjuvant analgesics will be needed.

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## For Help with Relieving Pain

Pain relief can significantly improve the quality of life for patients and their families. Most patients' pain can be managed with currently available medical knowledge and treatment. Physicians can acquire the knowledge and skills necessary to provide such relief fairly readily.

A physician who needs assistance in relieving pain in terminal illness should consider the following:

- ♦ Contact the Michigan Hospice and Palliative Care Organization, call 1-800-536-6300, or go to [www.mihospice.org](http://www.mihospice.org) for a referral to a hospice medical director, palliative care physician or a pain specialist.
- ♦ Check the resource section at the end of this chapter for additional materials including websites.

## Managing Symptoms Other Than Pain

Managing pain is often the main goal of physical care for patients at the end of life. Many patients, however, also suffer from other distressing physical symptoms that may be even more challenging to relieve than pain. A physician should assess these symptoms while keeping in mind the needs of the whole person.

In some cases, finding out the exact cause of a physical symptom may lead to better treatment. For many terminally ill patients, however, identifying the exact cause is not always necessary or helpful in deciding upon a treatment plan. Testing can be exhausting and burdensome for the patient and may be in conflict with the patient's personal goals at this important time of life. Fortunately, most physical symptoms can be managed effectively without knowing their exact cause.

### Difficulty with Breathing

At the end of life, shortness of breath and difficulty with breathing can be very troublesome and frightening to patients and family members.

When breathing problems get worse, or new ones develop, a search should be made for causes such as heart failure, infection or fluid collection that may be improved with specific medical treatment.

Even when specific treatments cannot be identified or are not effective, relief can be provided in most cases. Opioids (narcotics) are very effective in treating breathlessness in most patients. Benzodiazepines also may be considered, particularly for relief of anxiety associated with breathlessness. Oxygen may be helpful for some patients.

Comfort measures also should be considered, such as using a comfortable chair with support for sitting up, use of a dehumidifier or fan, subdued lighting and soothing music. Most important of all for many patients is comfort from the calming presence of family and friends.

### Constipation

Patients who are approaching the end of life may become constipated more easily because of inactivity and decreased intake of fluid and fiber. Constipation also is an expected side effect from the use of opioids. Doctor Cicely Saunders often said, "The hand that writes the opioid prescription should write the laxative prescription."

The consequences of unmanaged constipation may include abdominal discomfort, nausea and vomiting, and an obstructed bowel. It is important to remember that constipation is much easier to prevent than to treat. Patients and families should be instructed to report signs of constipation as soon as any symptoms occur.

Most patients at the end of life, however, need aggressive management. Regular use of stimulant or osmotic laxatives will manage most patients. Sometimes suppositories, enemas and manual removal are needed.

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## Nausea and Vomiting

At the end of life, many patients lose interest in eating. They also may become nauseated more easily and vomit more readily. These symptoms may have multiple underlying causes. Medications should be reviewed to see if they may be contributing to these distressing symptoms and then eliminated or changed, if possible.

Symptoms usually can be relieved with anti-nausea medications. Treatment should begin with medication aimed at the most likely cause, but a physician may need to try more than one medication to find what works best. See the separate list of other possibilities to help manage loss of appetite, nausea and vomiting.

## Anorexia and Weight Loss

A patient's loss of appetite and weight loss sometimes can be more upsetting to families and friends than to the patient. It is difficult to watch a loved one waste away, especially since many cultures strongly associate so much meaning regarding love and nurturing to the act of feeding.

Many patients with terminal illness, however, have little or no interest in food. Artificial nutrition, whether intravenous or enteral, usually does not improve the course of an illness. Being forced to eat and drink, in fact, may create considerable distress, including nausea and abdominal pain. Patients with little appetite often greatly enjoy what they do want to eat, but in small amounts.

## Fatigue and Weakness

It is natural for patients at the end of life to tire easily and have less energy. Patients should be evaluated for depression and other underlying causes. Medications for pain and anxiety also can contribute to fatigue, and adjustments to them may be helpful. The underlying role of the disease should be clarified to the patient and family.

Symptoms of fatigue and weakness are not easily treated with medications, but some patients may benefit from corticosteroids and psychostimulants. Promote energy conservation and give permission to rest.

## Cognitive Changes

Cognitive changes such as confusion, disorientation, irritability and agitation are common at the end of life

and can be frightening to patients and family members. These symptoms often fluctuate and the cause(s) are not easily determined or treated. The treatment goal is to relieve distress as much for the family as for the patient.

Medications may cause cognitive changes or make them worse. An effort should be made to adjust them carefully in order to effectively manage other symptoms while reducing troublesome cognitive changes. Elderly patients are particularly vulnerable to this problem.

Agitation, confusion and anxiety can be treated with tranquilizing medications to help reduce symptoms. These symptoms also can be reduced by a family caregiver's reassuring presence and a calming environment. Attention to spiritual concerns also is important.

### Helping a Patient with Anorexia, Nausea and Vomiting

- ♦ **Assess the level of symptom distress. Sometimes the patient is relatively comfortable, but the family is distressed. Assess the family's needs also.**
- ♦ **Address underlying causes including constipation, dehydration or electrolyte imbalances, infections in the mouth, anxiety and depression.**
- ♦ **Educate and support family caregivers. Help them understand the normal progression of the disease. Identify things they can do to help.**
- ♦ **Explore the emotional and psychological meaning of the patient's not eating.**
- ♦ **Offer his or her favorite foods.**
- ♦ **Use nutritional supplements if agreeable.**
- ♦ **Eliminate unnecessary dietary restrictions.**
- ♦ **Reduce portion sizes and make food look appetizing.**
- ♦ **Avoid disagreeable odors.**
- ♦ **Maintain a comfortable environment, including room temperature, lighting and noise level.**

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## **Pain and Symptom Management — Just One Aspect of Care**

Good pain and symptom management at the end of life brings obvious relief and unquestioned benefits to a patient and family members. Additionally, relief of physical suffering allows tremendous opportunity for growth and personal development in the patient.

The relief of pain may allow a patient to bring any healing needed to relationships, to say goodbye, to reminisce and to put accomplishments, joys and sorrows in perspective. It may allow a patient to gain clarity and a sense of completion about his or her life. A physician who skillfully relieves physical distress plays a pivotal role in making these growth opportunities real for a dying patient.

Effective pain and symptom management is just one aspect of improving the quality of life for a dying patient. The next chapter looks at palliative care, caring for the whole person—mind, body and spirit.

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# Pain Management Resources

## Websites

- ♦ [www.cancer.gov/cancertopics/coping](http://www.cancer.gov/cancertopics/coping)—National Cancer Institute latest information about pain, fatigue, and other complications/side effects.
- ♦ [www.learn.chm.msu.edu/painmanagement/index.asp](http://www.learn.chm.msu.edu/painmanagement/index.asp)—Michigan State University College of Human Medicine’s website for core competencies in pain relief for terminally ill patients.
- ♦ [www.eperc.mcw.edu/EPERC/FastFactsIndex](http://www.eperc.mcw.edu/EPERC/FastFactsIndex)—Fast Facts are intended to be quick teaching tools for bedside rounds and self-study materials for health care professional trainees and clinicians.
- ♦ [www.michigan.gov/mdch/0,1607,7-132-27417\\_45947---,00.html](http://www.michigan.gov/mdch/0,1607,7-132-27417_45947---,00.html)—The Michigan Department of Community Health’s Pain Management website that was developed to increase the general public’s and health professional’s awareness of pain and symptom management.
- ♦ [www.mipain.org](http://www.mipain.org)—The Michigan Cancer Pain Initiative (MCPI) is an association of health professionals, patient advocates, and representatives of clergy, government, and higher education, dedicated to addressing the problem of unrelieved pain from cancer and other sources.

## Books

- ♦ Eduardo Bruera, Charles E. Von Gunten, Irene J. Higginson, Carla Ripamonti. *Textbook of Palliative Medicine*. ©2009.
- ♦ Geoffrey Hanks, Russell K. Portenoy, Marie Fallon et al. *Oxford Textbook of Palliative Medicine*. 2010 Fourth Edition.
- ♦ Quill T, Holloway R et al. *Primer of Palliative Care*. Glenview IL, 2007 American Academy of Hospice and Palliative Medicine.
- ♦ T. Declan Walsh, Kathleen M. Foley, et al. *Palliative Medicine*. ©2008.

## Articles

- ♦ William Breitbart; Yesne Alici. *Agitation and Delirium at the End of Life: “We Couldn’t Manage Him”*. JAMA, December 24/31, 2008; 300: 2898 - 2910.
- ♦ James F. Cleary. *The Pharmacologic Management of Cancer Pain*. Journal of Palliative Medicine. December 2007: 1369-1394.
- ♦ Debra B. Gordon; June L. Dahl; et al. *American Pain Society Recommendations for Improving the Quality of Acute and Cancer Pain Management: American Pain Society Quality of Care Task Force*. Arch Intern Med, Jul 2005; 165: 1574 – 1580.
- ♦ Lorenz, K.; Lynn, J.; Morton, SC.; Dy, S.; Mularski, R.; Shugarman, L.; Sun, V.; Wilkinson, A.; Maglione, M.; Shekelle, PG. *End-of-Life Care and Outcomes*. View at the Agency for Healthcare Research and Quality at [www.ahrq.gov/downloads/pub/evidence/pdf/eolcare/eolcare.pdf](http://www.ahrq.gov/downloads/pub/evidence/pdf/eolcare/eolcare.pdf).
- ♦ Gordon J. Wood; Joseph W. Shega; Beth Lynch; Jamie H. Von Roenn. *Management of Intractable Nausea and Vomiting in Patients at the End of Life: “I Was Feeling Nauseous All of the Time...Nothing Was Working”*. JAMA, September 12, 2007; 298: 1196 - 1207.

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## FOR MY PATIENTS

**End-of-Life Care: Communicating With Your Doctor** (this example is to communicate about pain, but this form could be used for any physical symptom that you want to communicate with your physician about).

### Help Your Doctor Understand Your Pain

To help your doctor better understand your pain and help you find relief, think about the following questions and be prepared to answer them for your doctor or nurse.

- How severe is the pain? Many doctors and nurses use a pain scale: they will ask you to rate your pain on a scale from 0 to 10, where 0 is no pain at all and 10 is the worst pain you can imagine.
- Where is the pain? Does it spread or travel to other parts of your body?
- When did the pain start? Has it gotten better or worse? Is the pain steady or does it come and go?
- What does the pain feel like? Is it sharp or stabbing? Dull and aching? Burning?
- What makes the pain better? What makes it worse?
- What pain medications have you tried in the past? How effective were they? Did they cause side effects or problems? Have you used any other treatments?
- How is the pain affecting your life now? Is the pain keeping you from doing the things you want to do? How are you coping emotionally with the pain? How is your family coping?
- How is the pain affecting your life now? Is the pain keeping you from doing the things you want to do? How are you coping emotionally with the pain? How is your family coping?



# END-OF-LIFE

# Care



## Chapter 4

Palliative Care

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## Chapter 4: Palliative Care

### A Vision for Better Care at the End of Life

Palliative care, according to the World Health Organization (WHO), is the active total care of a patient whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual concerns are the primary goals of care. Many aspects of palliative care are applicable early in the course of a terminal illness.

The WHO states that palliative care:

- ♦ Aims to achieve the best possible quality of life for patients and their families
- ♦ Affirms life and regards dying as a normal process
- ♦ Neither hastens nor postpones death
- ♦ Provides relief from pain and other distressing symptoms
- ♦ Integrates the psychological and spiritual aspects of patient care
- ♦ Offers a support system to help the family cope during the patient's illness and in subsequent bereavement.

#### Last Acts Five Principles of Palliative Care

The Last Acts organization, a coalition of 400 organizations representing health care providers and patients nationwide, believes that everyone can make a difference in the care given to dying people and their families.

Five Principles of Palliative Care have been developed by the Last Acts Task Force on Palliative Care and the Family. These principles may seem just common sense. However, when taken together, they provide a new and more complete way to look at end-of-life care.

#### The Physician's Role in Palliative Care

Physicians have an ethical obligation to relieve pain and suffering and to promote the dignity and autonomy of dying patients in their care.



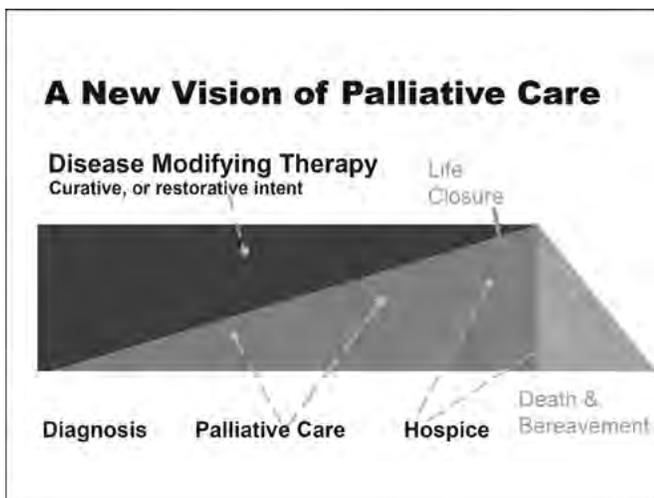
#### Five Principles of Palliative Care

- ♦ Palliative care respects the goals, likes and choices of the dying person
- ♦ Palliative care looks after the medical, emotional, social and spiritual needs of the dying person
- ♦ Palliative care supports the needs of the family members
- ♦ Palliative care helps gain access to needed health care providers and appropriate care settings
- ♦ Palliative care builds ways to provide excellent care at the end of life.

The American Medical Association's Code of Medical Ethics states patients must not be abandoned once it is determined cure is impossible. Patients nearing the end of life must receive good communication, emotional support, comfort care, adequate pain control and respect for their wishes, goals and values.

Near the end of life, physicians need to accompany and guide their patients through this critical transition. This includes:

- ♦ Providing the best estimates of prognoses
- ♦ Identifying situations where palliative care reasonably might supersede the desire for aggressive therapy
- ♦ Giving permission to patients to forego further aggressive treatment.



## Making the Transition from Curative to Palliative Care

Palliation of symptoms is a primary focus of care for terminally ill patients. But that does not mean the tools of palliative care should be withheld when a cure is still possible. Curative and palliative care can go hand in hand. Relieving pain and other difficult symptoms is a worthwhile goal at any stage; and doing so may also help the body respond more effectively to curative treatments.

Avoiding an either/or approach to palliative and curative care can also make decision-making easier when

the time comes to accept that cure is no longer the goal. Comfort care is less likely to be associated with abandonment or giving up hope when it has been part of the earlier treatment plan.

But making the decision to end curative treatments will still be difficult in many cases. Physicians, patients and families naturally resist accepting the imminence of death, and medicine's inability to predict precisely when death will occur may add an element of confusion.

Physicians can follow a suggestion from Americans for Better Care of the Dying (ABCD) and ask themselves, "Would I be surprised if this patient died this year?" When death seems a real possibility, it is important to make sure that the goals of care are built around the wishes and concerns of the patient.

ABCD further recommends that physicians ask the patient, "What do you hope for as you live with this condition? What would be left undone in your life? How are things going for you and your family?" The answers will also guide the development of a plan of care. The patient's concerns can usually be addressed by a combination of symptom relief, family support, continuity of care, advance planning and spiritual care, provided by the physician and other members of the care team.

Talking about the patient's goals, wishes and concerns will also help clarify their attitudes toward the use of potentially life-prolonging measures such as transfusions, antibiotics, feeding tubes and cardiopulmonary resuscitation. Some may be willing to pay a high price in quality of life in order to live a few additional days or weeks; others may not.

Other factors such as cultural norms or family dynamics may also affect a patient's decisions about ceasing curative or life-prolonging treatments. And patients with severe cognitive impairment may present additional and unique challenges. But, in fact, the transitions and decisions will follow an individual course for every patient according to the particulars of his or her life, which makes the physician's ability and willingness to listen all the more important.

For more information about palliative care, visit the websites listed at the end of this chapter. Withholding or withdrawing treatment is discussed in the next chapter, and hospice care is the focus of Chapter 6.

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## Physician Requirements of the Michigan Dignified Death Act

The Michigan Dignified Death Act (1996 Public Act 594) is an informed consent law intended to increase the awareness of a patient with a reduced life expectancy due to advanced illness of their rights to decide whether to receive, continue, discontinue or refuse medical treatment.

The act requires a physician who recommends medical treatment for a person with a reduced life expectancy due to advanced illness to inform the patient, the patient's surrogate decision-maker or patient advocate—both orally and in writing— about the recommended treatment and alternatives. This includes giving information about the advantages, disadvantages and risks of the recommended treatment and each alternative, and about the specific procedures involved.

It also requires a physician to provide information about palliative care, including hospice and pain management. The law provides certain immunities for compliance and offers certain liability protections when prescribing controlled substances.

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## Palliative Care Resources

### Websites

- ♦ **www.abcd-caring.org**—Americans for Better Care of the Dying (ABCD) is dedicated to social, professional and policy reform aimed at improving the care system for patients with serious illness and for their families.
- ♦ **www.capc.org**—Center to Advance Palliative Care (CAPC) provides health care professionals with the tools, training and technical assistance necessary to start and sustain successful palliative care programs in hospitals and other health care settings.
- ♦ **www.dyingwell.org**—Dying Well website lists resources and referrals to empower persons with life-threatening illnesses and their families to live as fully as possible during the dying process.
- ♦ **www.growthhouse.org**—Growth House: Guide to Death, Dying, Grief, Bereavement and End-of-Life Resources offers search engine access to the Internet's most comprehensive collection of reviewed resources for end-of-life care.

### Books

- ♦ Eduardo Bruera, Charles F. Von Gunten, Irene J. Higginson, Carla Ripamonti. *Textbook of Palliative Medicine*. ©2009.
- ♦ Geoffrey Hanks, Russell K. Portenoy, Marie Fallon et al. *Oxford Textbook of Palliative Medicine*. 2010 Fourth Edition.
- ♦ Quill, T.; Holloway, R.; et al. *Primer of Palliative Care*. *American Academy of Hospice and Palliative Medicine*. Glenview IL, 2007.
- ♦ Morrison, RS.; Meier, DE. *Palliative Care*. *N Engl J Med* 350:2582, June 17, 2004.
- ♦ Joan M. Teno; Stephen R. Connor. *Referring a Patient and Family to High-Quality Palliative Care at the Close of Life: "We Met a New Personality...With This Level of Compassion and Empathy"* *JAMA*, February 11, 2009; 301: 651 - 659.
- ♦ T. Declan Walsh, Kathleen M. Foley, et al. *Palliative Medicine*. ©2008.



## FOR MY PATIENTS

### End-of-Life Care: Finding Personal Comfort

#### Seeking Comfort in Relationships and Activities

People who are approaching the end of life may have personal matters or relationships that are not settled. An unsettled situation can prevent you from being in a comfortable frame of mind. These situations may not be apparent to your physician, family or friends unless questions are directly asked. Some questions to consider and then discuss with others include:

- Is there something you would like to do before you get too sick?
- Many people have old differences they would like to settle before they die. Is there anyone you want to be able to see or talk to before you die?
- Many people have places or people they would like to visit. Do you?
- Some people have a piece of work they would like to finish. Do you?
- In what ways has this illness affected you emotionally?
- Are you doing things you enjoy? What would you like to do today? Tomorrow?
- How has your mood been lately?
- How have you been coping with all of this?
- How have you handled stress in your life?
- Are you concerned about being a burden to others?
- Do you feel you have control in your life now?

#### When Time May Be Short

Some things to think about doing when time may be short include:

- Spend time with people who are important to you.
- Create a legacy for those who care about you. Letters, a tape recording or a video can be a special gift for your children and grandchildren.
- Call or ask an old friend to visit and tell your story to those who live on.
- Accept some compliments and gratitude.
- Forgive yourself and seek to make things right within your own faith.
- Say “I love you,” “I’m sorry,” “Forgive me,” and “I forgive you.”
- Right old wrongs.
- Take a last trip or two.
- Make time for spiritual issues and struggles.
- Say good-bye.
- Eventually, be at peace with the end to come and the uncertainty of when you will die.
- Make plans to ensure that your care and treatment will be as close as possible to what you want.

Adapted from the website [www.completingalife.msu.edu](http://www.completingalife.msu.edu). Reprinted with permission.



# END-OF-LIFE

# Care



## Chapter 5

Withdrawing or Withholding Specific Treatments

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## Chapter 5: Withdrawing or Withholding Specific Treatments

### Treatment Goals Can Increase Peace and Comfort



When it becomes apparent that a patient is approaching the end of life, or that prolonging life is no longer desired by a patient, a decision can be made to stop (withdraw) or not start (withhold) further curative or life-prolonging therapies. Life sustaining treatment may include, but is not limited to, mechanical ventilation for breathing, renal dialysis for kidney functioning, chemotherapy for cancer treatment, antibiotics for infections and artificial nutrition and hydration for food and water.

At first, a decision to withdraw or withhold specific treatments may seem like giving up. But when physicians, patients and family members communicate effectively as a team, it can be very satisfying and empowering. As treatment goals are clarified based on the values of the patient, peace and comfort can be increased in the face of death.

### Withdrawing or Withholding Medical Treatment

Several factors are involved in making a decision to withdraw or withhold therapy. The voluntary choice of a patient or patient advocate should determine when life-sustaining therapy is started or stopped. To make informed choices, patients need to know that decisions must be made and they need to have accurate information about treatment options. The same is true when a patient advocate or other surrogate decision-maker must decide for a patient who cannot communicate his or her own wishes.

There is no ethical or legal difference between withdrawing (stopping) or withholding (not starting) a medical therapy. Not only must physicians and patients remain free to try new therapies and determine their effectiveness, but they also must be free to discontinue

therapies that fail to achieve their goals or become too burdensome. Physicians are not ethically or legally required to provide therapies that have no benefit and are considered medically futile.

When starting a new therapy, a specific timeframe for assessing its efficacy in meeting the patient's goals should be agreed upon. Those goals can be used to make a decision about whether to continue or stop the treatment. To avoid misunderstandings and conflicts, physicians should document all discussions with patients and families about starting or stopping therapies.

See the next chapter on hospice care for more information about working with patients who have decided to forego curative care.

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## Withdrawing or Withholding Treatment Resources

### Articles

- ♦ American Medical Association Council on Ethical and Judicial Affairs. “*Decisions Near End of Life.*” JAMA. 1992;267:2229-2233.
- ♦ American Medical Association Council on Ethical and Judicial Affairs. “*Decisions to Forgo Life-Sustaining Treatment for Incompetent Patients.*” In: Council on Ethical and Judicial Affairs Reports on End-of-life Care: 1998: 30-40.
- ♦ American Medical Association Council on Ethical and Judicial Affairs. “*Do-Not-Resuscitate Orders.*” In: Council on Ethical and Judicial Affairs Reports on End-of-life Care: 1998:1.
- ♦ Anthony L. Back; Robert M. Arnold. *Dealing With Conflict in Caring for the Seriously Ill: “It Was Just Out of the Question.”* JAMA, March 16, 2005; 293: 1374 - 1381.
- ♦ Casarett, D; Kapo, J; Caplan, A. *Appropriate Use of Artificial Nutrition and Hydration — Fundamental Principles and Recommendations.* N Engl J Med 353:2607, December 15, 2005.
- ♦ Neil J. Farber; Pamela Simpson; Tabassum Salam; Virginia U. Collier; Joan Weiner; E. Gil Boyer. *Physicians’ Decisions to Withhold and Withdraw Life-Sustaining Treatment.* Arch Intern Med, Mar 2006; 166: 560 - 564.
- ♦ Thomas J. Prendergast; Kathleen A. Puntillo. *Withdrawal of Life Support: Intensive Caring at the End of Life.* JAMA, Dec 2002; 288: 2732 - 2740.

### End-of-Life Care: Withdrawing or Withholding Specific Treatments

## Withdrawing or Withholding Medical Care Is Not Euthanasia

**Q. Do physicians, by law, have to give all life-sustaining care possible?**

**A.** No. If a patient and physician believe that a medical treatment does not meet the patient's goals for therapy, there is no ethical or legal requirement to provide that care—including life-sustaining treatments. A patient also has a right to refuse any medical treatment recommended by his or her physician, even life-sustaining treatments.

**Q. Is withdrawal or withholding medical care considered euthanasia?**

**A.** No. Withdrawal or withholding of treatment is a decision to allow a disease to follow its natural course, which may result in a patient's death. Euthanasia, on the other hand, is a conscious decision to take actions with the specific intent to end a patient's life.

**Q. Are you killing a patient when you remove the ventilator (breathing machine) or other life-sustaining treatments?**

**A.** No. The patient is dying from the main illness, not the removal of care. It is okay for a patient to refuse ventilator treatment, or for a physician to declare that a treatment is not working. The patient and physician may make a similar decision about continuing with the treatment.

**Q. Is the use of strong pain medication considered to be euthanasia?**

**A.** No. The danger of causing death by using strong medications for a patient with pain generally is overrated. The usual medications for pain, called opioids, are a very poor choice for attempted drug-induced death. Even large and rapid increases in strong medication when needed to control a patient's pain are very unlikely to lead to death.

**Q. Is it illegal for a doctor to prescribe strong doses of medications to relieve pain, shortness of breath or other symptoms?**

**A.** No. There is no upper limit to the dose of medication that is both permitted and appropriate if the intent and doses given are right for a patient's needs.



# END-OF-LIFE *Care*



## *Chapter 6*

Hospice: A Team Approach to Care

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## Chapter 6: Hospice: A Team Approach to Care

### Comfort, Respect and Dignity in Dying



**H**ospice care provides patients and family members with hope, comfort, respect, and dignity with a focus on living as fully as possible while dying. With hospice, patients and family members have assurance they will have caring professionals on their side as guides on their final journey. And, they can be sure they will not have to face the unknown alone.

Hospice is a model of care specially tailored to the needs of terminally ill people and their families. It is comprehensive care, addressing the physical, emotional, social and spiritual needs of the patient, family and friends. Hospice personnel bring with them important and unique skills and resources. Using the home (whatever setting the patient considers as home) as the center for care, and family members as hands-on caregivers, hospice personnel provide both direct care and help with obtaining needed goods and services.

Trained volunteers add listening ears and provide practical help. Social workers provide compassionate assistance in coping with physical and emotional changes taking place and in finding needed special equipment, supplies and services. Physicians, nurses, allied health care professionals and support personnel provide in-home medical and nursing care. Spiritual caregivers are available to support everyone involved. Finally, hospice services include support for grieving family members for more than one year after the death of a loved one.

Besides being more humane and comforting to all those involved, dying at home, in hospice residences, or in hospice/palliative care units of hospitals and nursing homes is less costly than dying in acute care hospitals. Accordingly, Medicare, Medicaid, most insurance plans and HMOs cover hospice care. Many hospices receive support from their communities so they are able to provide services at no charge to people without insurance.

#### The Physician's Role in Hospice Care

All medical care, including hospice care, must be provided by or under the supervision of a physician. All hospices have medical directors and also work with physicians from all specialties. With the agreement of the patient and family, the hospice team will keep the referring physician involved in the care plan for the terminal illness. The hospice medical director may be consulted for assistance in challenging cases.

#### When to Call on Hospice

Hospice ideally becomes involved with patients and families during the final months of life. That is when the need for more specialized palliative care is usually greater, the amount of care needed increases, the demands on caregivers and families are heavier, and there is likely to be a need for additional equipment and services. Unfortunately, very late referrals to hospice are common, leaving only days or weeks for a hospice to adequately address the comprehensive needs of the patient and family.

The decision to call on hospice is an individual one for each patient and family. Because the financial, physical and

emotional burdens of caring for chronically ill and dying patients often become progressively more difficult, it is most practical to contact hospice sooner rather than later.

For terminally ill patients, the time to call hospice is when a decision has been made to focus on pain control, palliative care and comfort rather than continuing curative medical treatments. Though it is an individual choice—made ultimately by competent patients or their advocates—it is best when the decision is made collectively by the patient, family and physician.

Patients and families need their physicians' help. They usually need to hear an estimate of the length of life remaining. They also may want to know how death is likely to occur. And they may want to discuss the reasonable

effectiveness and potential benefits of curative treatment choices. The burdens of treatment options also should be discussed in terms of pain, inconvenience to the patient, disruption of life, effects on others, and the quality of remaining life, all of which depend on the success of the treatments. See Chapter 1 on communication and Chapter 5 on palliative care.

An individual's personal values and feelings about life, death and suffering are crucial elements in the timing of a decision to call on hospice.

## Choosing Hospice

Hospice care is appropriate once the decision is made to forego further curative treatment. Hospice can focus on palliative care and help the patient live to the fullest.

Though a hospice certification must have a physician's signature, the initial contact with a hospice may be made by a patient, a family member, a nurse or social worker. Most hospices provide an initial consultation visit without obligation for a patient not yet certain about the decision.

The hospice admission process involves obtaining relevant health care information about the patient. That

## Introducing Hospice Care to Your Patients

Talking to a patient about hospice care can be a delicate undertaking. Listed below are a few suggestions for delivering difficult news and initiating a discussion of hospice care:

- ♦ Choose a private area where there will be no interruptions. An unhurried presence will show more care and concern.
- ♦ Sit down with the patient and family members. Try to avoid discussing difficult news with the patient alone.
- ♦ Use simple language to offer an overview of the situation, the diagnosis and its implications. Make no assumptions about what the patient understands.
- ♦ Be prepared to repeat information when necessary. Allow time to recognize the emotional reactions of the patient and family members.
- ♦ Ask for and address specific concerns of the patient and family.
- ♦ Schedule a return visit in a day or two to allow the patient and family members to absorb information and ask any additional questions.
- ♦ Review "Six Steps to Communicating Bad News" in Chapter 1.

## The Process to Initiate Hospice Care

Initiating hospice care begins after a discussion about hospice has taken place and the patient and family have agreed to hospice care. Regardless of the location of the patient at the time of referral, a hospice program will need:

- ♦ Admitting diagnosis
- ♦ Prognosis—must be six months or less to be eligible for hospice
- ♦ Attending physician's order for hospice care
- ♦ Patient and family understanding of the disease and prognosis
- ♦ Orders for medications and treatments
- ♦ Current medical findings
- ♦ History and physical

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includes diagnosis and prognosis, medications and other treatments, laboratory and other diagnostic study reports, medical history and physical examinations, and relevant information about the patient, family and significant others.

Once a patient has been accepted for hospice care, the hospice team develops a treatment plan in concert with the patient, family and physician. Regular team and family meetings are held and the plan is revised as needed.

Neither physicians nor family members need to be overly concerned about hospice regulations if a patient is admitted to a hospice too soon. A patient may be admitted to a hospice program when his or her condition meets Medicare guidelines. The patient then may be discharged if there is improvement or if hospice services are no longer needed, and re-admitted in the future if hospice care is needed again.

## Conditions for Hospice Care

The criterion that must be met to qualify for hospice care is straightforward. A patient must, in the physician's best judgment, have six months or less to live if the disease runs its normal and expected course.

The Health Care Financing Administration (HCFA) requires that the physician re-certify that the patient meets this criterion after 90 days and then again after another 90 days. After that, re-certification is required every 60 days.

Hospice treatment goals are comfort and symptom management, along with helping the patient and family to live fully, rather than to focus on cure. That does not, however, prevent the palliative use of treatments traditionally viewed as curative, such as radiation or chemotherapy when needed to relieve symptoms.

The decision about whether or not to stay in hospice care remains with the patient, referring physician and the hospice medical director.

## Hospice Care Remains Underutilized

Hospices are available and accessible to those who need their services. Medicare, Medicaid and most third-party health insurance benefits cover hospice care. Often where community support is strong, hospice is available at reduced rates or free to those without insurance.

Unfortunately, hospice remains an underutilized resource of care and comfort. In Michigan, the average length of stay for patients in hospice is well under two months and the median length of stay is under a month. Many patients use hospice services for less than one week. Generally, it takes at least a month for a patient, family and hospice team members to become comfortable working together. More importantly, it takes time for the patient to decide how to handle life closure issues. Such short stays prevent patients and families from receiving the full benefits of hospice care.

The most obvious reason for under-utilizing hospice care is a delay in making the decision to focus on comfort, rather than cure. Physicians, patients and families often find it difficult to face end-stage illness and death. It is not easy to abandon hope for a cure and begin to focus on comfort and completing the tasks of ending life and preparing for death. What patients and families need most at the end of life are comfort, support and assistance in completing the tasks of dying.

Patients, and everyone close to them, may know that death is approaching, but sometimes no one is willing to talk about it. Paradoxically, a source of immediate comfort for patients and families is the sense of relief experienced once they make the decision to call on hospice and focus on living while dying.

## Levels of Hospice Care

When a patient chooses hospice care, an interdisciplinary team of physicians, nurses, social workers, spiritual care counselors, home health aides and volunteers deliver care. This team provides pain management and comfort care for the patient, and emotional and spiritual support for the patient and family.

Hospice care falls into four main levels:

Level I—Routine Home Care—all care delivered in the patient's home, including patients who reside in nursing facilities.

Level II—Respite Care—brief care in a facility setting to give the family respite from caregiving.

Level III—Continuous Care—intensive medical and nursing care in the home when pain and other symptoms are in need of control.

Level IV—Inpatient Care—care provided in a facility setting when pain and other symptoms cannot be controlled in the home.

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## Hospice Resources

### Web Sites

- ♦ [www.hospicefoundation.org](http://www.hospicefoundation.org)—Hospice Foundation of America’s website includes newsletters, information and other support.
- ♦ [www.mihospice.org](http://www.mihospice.org)—Michigan Hospice and Palliative Care Organization’s website includes list of and links to all hospice organizations in Michigan.
- ♦ [www.nhpco.org](http://www.nhpco.org)—National Hospice and Palliative Care Organization is a resource for professionals and volunteers committed to and providing service to patients and their families during end of life.

### Articles

- ♦ David J. Casarett and Timothy E. Quill. *“I’m Not Ready for Hospice”: Strategies for Timely and Effective Hospice Discussions.* *Ann Intern Med* 2007 146:443-449.
- ♦ Gazelle, G. Understanding Hospice — *An Underutilized Option for Life’s Final Chapter.* *N Engl J Med* 357:321, 2007.
- ♦ Wright, AA.; Katz, IT. *Letting Go of the Rope — Aggressive Treatment, Hospice Care, and Open Access.* *N Engl J Med* 357:324, 2007.

### Booklets

- ♦ *Hospice Care: A Physician’s Guide.* Michigan Hospice & Palliative Care Organization. An 86- page booklet on hospice care including Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases. Call 1-800-536-6300.
- ♦ *Hospice Services Guidelines and Definitions.* National Hospice and Palliative Care Organization. Call 1-800-658-8898.

### End-of-Life Care: Hospice: A Team Approach

#### Making a Decision to Use Hospice Services

One of the biggest decisions for you to make when considering hospice care is to focus on comfort rather than cure. This decision requires you to openly discuss your goals, plans, loves, hopes and fears with your family and physician so plans can be made to help you live to the fullest for the rest of your life. Usually, you or your family can arrange a visit with a hospice social worker, nurse or physician to discuss your condition, prognosis and options for treatment, and to learn what hospice has to offer.

#### Hospice Care in Michigan

There are more than 90 hospice programs in Michigan operating from about 100 locations with at least one hospice serving every county. To locate a hospice resource, call the Michigan Hospice and Palliative Care Organization at 517-668-6396, or visit their web site at [www.mihospice.org](http://www.mihospice.org).

#### Paying for Hospice Care

Hospice services are covered by most insurers, including Medicare, Medicaid, Blue Cross Blue Shield of Michigan, many private insurers and HMOs. Most costs, with the exception of some co-pays for prescriptions, are covered by most policies.

It is important to note that many hospices accept patients who have no insurance or no other way to pay for their care. Hospice organizations use volunteers, sponsor fundraisers and get funding in many other ways, including community groups and grants, to help cover their costs.

#### Services Covered by the Hospice Medicare Benefit

The majority of hospice patients are eligible for the Medicare Hospice Benefit, which pays for:

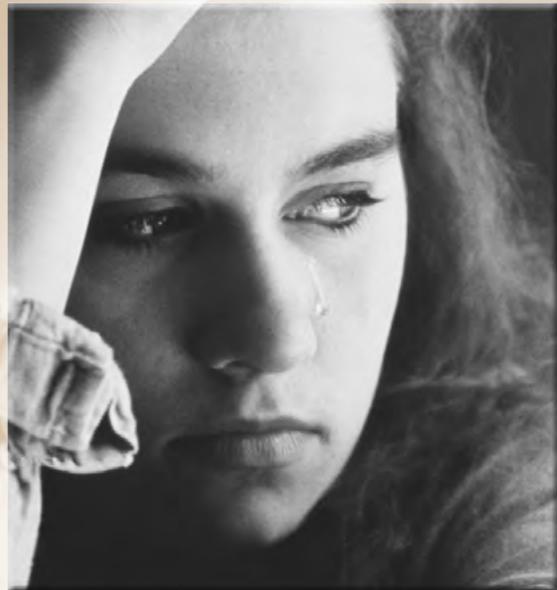
- ♦ Hospice medical director
- ♦ Nursing care
- ♦ Home health aide services
- ♦ Social worker services
- ♦ Medical equipment
- ♦ Medical supplies
- ♦ Medications for symptom control and pain relief
- ♦ Short-term care in the hospital, including respite care
- ♦ Grief counseling
- ♦ Services for patient and family by trained volunteers
- ♦ Physical and occupational therapy
- ♦ Speech therapy
- ♦ Dietary counseling

If you or your family members have any questions about hospice, please feel free to ask your physician or his or her staff. You need all of the information possible to make the decision that is right for you.



# END-OF-LIFE

# Care



## Chapter 7

Emotions, Spirituality and  
the Tasks of Dying



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## Chapter 7: Emotions, Spirituality and the Tasks of Dying

### Treating the Whole Person, Not Just the Illness

Physicians have a responsibility to treat each patient as a whole person. Symptoms of pain and physical distress can be largely relieved as outlined earlier. Addressing psychosocial and spiritual needs can be more challenging.

As death approaches, patients' personal projects and social responsibilities have to be reconsidered. Depending on their individual situations, dying patients are likely to feel some frustration, sadness and perhaps anger at the way things turned out. And, depending on how much they value independence, they may fear—and be angry about—losing control over the ability to care for themselves or becoming dependent on others.

The end of life also brings a loss of relationships with others. Those surviving will be permanently changed. Family members, friends and physicians all may feel a mixture of anxiety, love, sadness and anger. Everyone involved needs to be sensitive to their own emotions and the emotional and spiritual needs of the others.

#### Focus on Living to the Fullest

Once the team of patient, family, physician and other health care professionals accept that death will occur in the foreseeable future, they are free to concentrate together on living fully until death occurs. Physicians can assure that any new medical treatments or procedures are designed to help the patient find comfort and peace.

Patients should be encouraged to concentrate on tasks they want to complete in the time they have left. Some may be mechanical, such as updating or completing a will or a durable power of attorney for health care. Some may be spiritual, such as finding and making peace with oneself or one's god, and may require the assistance of clergy. Other tasks involve resolving old personal and emotional issues, hurts and animosities. This includes asking for and receiving forgiveness from oneself or others.

Depending on a patient's comfort and strength, visits can be made to favorite places and friends to reminisce,



give thanks and say good-bye. A written, audio or videotaped record can be created as a permanent legacy that contains statements of the dying patient's values and lessons learned in life and while dying. Team members also may want to develop some unique practices and rituals, like setting times together to reminisce, laugh and cry, or share meditation or prayer.

#### The Physician's Role

Physicians have multiple responsibilities in caring for a patient at the end of life. They must treat the whole person, not just the disease. It is critical that physicians assess their patients' spiritual and emotional needs. These needs are important in their own right, and may contribute to physical symptoms as well. Physicians need not manage all of their patients' psychosocial and spiritual needs themselves; they can call on hospice and other professionals for help.

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## Healthy Grieving

Healthy grieving is a long and complex process of emotional and spiritual recovery following the death of a loved one. It is best to begin the process before death. Healthy grieving begins when the entire team of patient, family, physician and other health care professionals work together to prepare for death.

In varying degrees, everyone involved with caring for a dying patient faces a spiritual crisis of personal redefinition and the need to grieve. The dying patient is challenged to find meaning in life and redefine his or her goals as death approaches. The family is challenged to begin to consider life without a loved one. The physician needs to grieve the impending loss of a patient whom he or she may have tried valiantly to save and who also may be a friend.

For families and friends, there are no shortcuts through the pain of loss and on to renewed emotional and spiritual health. Healthy grieving requires recognizing appropriate feelings of sadness and loneliness. For families that use them, hospices provide assistance with grieving for at least 13 months after the death of a loved one.

The same techniques that were useful for dealing with emotions surrounding approaching death also can help with healthy grieving. Visiting favorite places, reminiscing with friends, meditation and prayer can facilitate the grieving process. New rituals and ceremonies might be beneficial, such as having an imaginary conversation with the person who died and establishing memorial celebrations of the loved one's life on important anniversaries.

While it may not seem possible at the time of death, families will eventually find new meaning in life and be able to have fun and laugh again.

Physicians also need ways to process their grief. Depending on the circumstances, a physician can grieve a patient's death in a healthy manner by calling family members or sending them a note to express condolences, attending the visitation, funeral or memorial service.

## Emotional Response to a Terminal Illness

After learning of a terminal illness and then dealing with its reality, patients tend to experience a range of emotions. It is important to ask how they are responding to the illness. Help them name their emotions— common ones include:

- ♦ Anger
- ♦ Grief
- ♦ Depression
- ♦ Fear

Actively listen to and acknowledge patients' feelings. This normalizes their experiences and allows them to move toward acceptance.

Nearly all patients have fears as they near the end of life. These fears are important to recognize. They include:

- ♦ Loss of control
- ♦ Loss of dignity
- ♦ Loss of relationships
- ♦ Physical suffering

## Assessing the Spiritual Needs of the Patient

Most people have some spiritual component to their lives. For some, spirituality may play an important role in daily activities. For others, spirituality is not readily apparent, but is nonetheless important. It is valuable to determine a patient's individual interpretation of spirituality. Spirituality is not always about "organized" religion—it really is about what gives meaning to life for an individual.

Christina Puchalski, MD, has designed a short spiritual history that can be used to assess a patient's spirituality and related needs.

### Taking a Spiritual History

1. Consider spirituality as a potentially important component of every patient's physical well-being and mental health.
2. Address spirituality at each complete physical exam and continue addressing it at follow-up visits if appropriate. In patient care, spirituality is an ongoing issue.
3. Respect a patient's privacy regarding spiritual beliefs. Don't impose your beliefs on others.
4. Make referrals to chaplains, spiritual directors or community resources as appropriate.

### Spiritual Assessment Tool

The acronym FICA can be used to help remember what to ask in a spiritual history:

- F:** Faith or beliefs
- I:** Importance and influence
- C:** Community
- A:** Address issues

Some specific questions you can use to discuss these issues are:

**F:** What is your faith or belief?

Do you consider yourself spiritual or religious?

What things do you believe in that give meaning to your life?

**I:** Is spirituality important in your life?

What influence does it have on how you take care of yourself?

How have your beliefs influenced your behavior during this illness?

What role do your beliefs play in regaining your health?

**C:** Are you part of a spiritual or religious community? If yes, is this of support to you, and how?

Is there a person or group of people you really love who are important to you now?

**A:** How would you like me to address these issues in your health care?

Source: Spirituality Assessment Tool, © 1999 by Christina Puchalski, MD. Reprinted by permission of the author.

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## Emotions and Spirituality Resources

### Whole Person Care

- ♦ *Dying Well: Peace and Possibilities at the End of Life*. Byock, I. New York: Riverhead Books: 1997.
- ♦ Chochinov HM. *Dignity and the Essence of Medicine: The A, B, C, and D of Dignity Conserving Care*. *BMJ*. 2007 Jul 28;335(7612):184-7.
- ♦ **www.dyingwell.org**—Dying Well is a website sponsored by Ira Byock, MD, a long-time palliative care physician and an advocate for improved end-of-life care. The site includes resources for people facing life-limiting illness, their families and their professional caregivers.

### Spirituality

- ♦ “Are You at Peace?": *One Item to Probe Spiritual Concerns at the End of Life*. *Arch Intern Med*, 2006; 166: 101 - 105.
- ♦ Allan S. Brett; Paul Jersild. “*Inappropriate*” *Treatment Near the End of Life: Conflict Between Religious Convictions and Clinical Judgment*. *Arch Intern Med*, Jul 2003; 163: 1645 – 1649.
- ♦ Lo B, Ruston D, Kates LW, et al. *Discussing Religious and Spiritual Issues at the End of Life: a Practical Guide for Physicians*. *JAMA*. 2002;287:749-754.
- ♦ Daniel P. Sulmasy. *Spiritual Issues in the Care of Dying Patients: ...It’s Okay Between Me and God*”. *JAMA*, Sep 2006; 296: 1385 - 1392.
- ♦ **www.gwish.org**—The George Washington Institute for Spirituality and Health supports clinical issues related to spirituality and health through research, education and policy work focused on bringing increased attention to the spiritual needs of patients, families and health care professionals.

### Physician Self-Care

- ♦ Nicole G. Chau; Camilla Zimmermann; Clement Ma; Nathan Taback; Monika K. Krzyzanowska. *Bereavement Practices of Physicians in Oncology and Palliative Care*. *Arch Intern Med*, 2009; 169: 963 - 971.
- ♦ Michael K. Kearney; Radhule B. Weininger; Mary L. S. Vachon; Richard L. Harrison; Balfour M. Mount. *Self-care of Physicians Caring for Patients at the End of Life: “Being Connected...A Key to My Survival”* *JAMA*.
- ♦ **www.meaninginmedicine.org**—Finding Meaning in Medicine offers the opportunity to speak openly with colleagues and to receive a level of support, understanding and insight that is unique to a physician group.

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## FOR MY PATIENTS

### End-of-Life Care: Emotional and Spiritual Issues

#### Finding Meaning in Your Life

People have found many ways to give meaning to their experiences at the end of life. Examples of things others have done to heal emotionally and grow spiritually are listed below.

#### Centering Yourself

There are many ways to center yourself and your thoughts, to quiet your mind and to see yourself as part of the whole world around you. You might ask a hospice or hospital chaplain or a social worker to help you find ways to meditate and reflect on your life. Talk with your spiritual leader about the benefits of prayer.

#### Gathering

Getting together with people you love and who are important to you can be very satisfying to you and to them. Organize a party and invite family and friends to share memories and stories. Such gatherings can be surprisingly happy and can give you a chance to say good-bye to people you have loved and enjoyed being with.

#### Giving

Some cultures prefer gift giving. Native Americans, for instance, give valuable keepsakes to signify the end of life. This activity allows the giver to show appreciation for the relationship shared with someone else.

#### Creating

You can give more than your material treasures to those you love. Making an audio or video tape of stories or memories—sharing your experiences with family members and friends—is a wonderful gift to you and your family. Discuss your values, hopes, insights, beliefs and wisdom, or just tell your story. This becomes both a cherished reminder of you and a way to continue your good will. A special photo album or a scrapbook also can help create memories of times you shared. Some people write letters to those who will survive them, particularly parents to their children.



## Acknowledgements

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Dedicated to Isabelle and all other patients who died in pain.

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