



*Physician Guide
to Hospice and Palliative Care*



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Introduction:

Finding Comfort and Peace at the End-of-Life

*Dear Doctor,
This booklet was created to provide information to physicians about hospice care and end-of-life issues. You can help your seriously ill patients and their families find comfort and peace in the last months of their lives by reviewing this guide and allowing it to serve as a source of information.*

One of the many advantages of hospice care that we have to offer is the expertise of the staff in symptom management. We offer holistic care with a focus on the relief of suffering--not only physical suffering, but emotional and spiritual distress as well. As the Medical Director of UHR, I am board certified in hospice and palliative care. I am available to provide consultation to you in caring for your patients. Please don't hesitate to call me at 845-357-7557.

You will read about our interdisciplinary team approach, and while we provide many services to patients, the entire family is considered our unit of care. We have included information in Chapter 1 that tells you how to make a referral to UHR and how to bill for services.

The comment that we hear too frequently from hospice patients and families is, "We wish we had known about hospice sooner." We hope that this booklet provides you the necessary information about hospice services. Thank you for working with us and allowing the hospice staff to help you care for your patients.

George R. Cox, MD

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Hospice:
A Team Approach to Care

Comfort, Respect and Dignity in Dying

Hospice 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 people and their families facing life-limiting illness. It is comprehensive care, addressing the physical, emotional, social and spiritual needs of the patient, family and friends. Hospice staff bring with them important and unique skills and resources. Using the home, nursing home (or whatever the patient considers a home) as the location for care, and family members as hands-on caregivers, hospice staff 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 the physical and emotional changes taking place and in finding needed services. Physician, nurses, allied health care professionals and support staff 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, or with hospice care at an area nursing home is less costly than dying in an acute care hospital. Accordingly, Medicare, Medicaid, most insurance plans and HMOs cover hospice care. United Hospice of Rockland receives support from our community so we are able to provide services on a sliding scale to people with inadequate insurance coverage.

The Physician's Role in Hospice Care

All medical care, including hospice care, must be provided by or under the supervision of a physician. United Hospice of Rockland has a medical director who works with community physicians from all specialties. The hospice team will keep you involved in the care plan for your patient. 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 hospice to adequately address the comprehensive needs of the patient and family.

The decision to utilize 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 seriously ill patients, the time to call hospice is when a decision has been made to focus on pain control, and comfort rather than continuing curative medical treatments. (Please do not make any assumptions about which treatments will or will not disqualify an individual from receiving hospice care. We want to review all potential referrals with you and evaluate how we can help.) 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. 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. 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.

The Mission of United Hospice of Rockland:

United Hospice of Rockland, Inc. (UHR) provides care, hope, comfort and improved quality of life to individuals and their families facing serious illness. We offer compassionate support to members of our community who have experienced the loss of a loved one. We lead the health and human services community in improving the provision of care to those affected by serious illness.

What are the Criteria for Admission?

- * The attending physician determines that the life expectancy is 6 months or less **if the disease runs its normal course.**
The hospice medical director upon reviewing the patient's history must also concur with the prognosis.
- * Hospice provides care for patients with any serious illness.
Examples include end-stage cardiovascular disease, pulmonary disease, renal disease, AIDS, Alzheimer's disease.
- * The patient/family express a desire and need for hospice services and is willing to sign an informed consent electing hospice care.

Services Provided by United Hospice of Rockland Include:

- * Comprehensive skilled nursing services including 24 hour on-call service.
- * Medical social services to address the psychosocial concerns of the patient and family.
- * Physician services in the absence of a primary care physician or for palliative care consultation with the primary physician.
- * Spiritual care services including coordination with local clergy.
- * Short-term acute inpatient care at contracted facilities for symptom management.
- * Medical equipment and supplies, including medications related to the terminal illness.
- * Personal patient care provided by Certified Home Health Aides.
- * Therapies (physical, occupational, speech, nutritional, music, massage, respiratory).
- * Volunteer services for support and respite.

Quotable

"The transition from curative care tends to be a cultural issue. There is reluctance on the part of the family, patient and medical system to face the fact that a person's disease may be incurable. It's easier to try another round of chemo or other therapies. Often patients still aren't ready - even when their physician suggests hospice as the plan of care. Physicians can ease the transition by introducing the issue of comfort or palliative care early on and in conjunction with the curative treatment plan. By doing so, it will be easier to go back to the issue of hospice care six months or one year later if the disease continues to progress and is not curable."

*~ Tom George, MD
Medical Director
Hospice of Greater Kalamazoo*

"Families are often concerned about how long their loved ones have to live. I tell them there are no pat answers. No one can completely predict these things. I have seen some patients live for months who should have died rapidly based on the extent of their disease, and others die quickly and unexpectedly. The key thing we can do at hospice is ensure that their final days are comfortable."

*~ Fred Isaacs, MD
Former Medical Director
Hospice of Lansing*

How to Make a Referral:

- * **Call in a referral 24 hours a day to 845-634-4974**
- * **Fax a referral to 845-634-7549**

After a referral is made to Hospice, a nurse will contact the prospective patient and family to schedule a time to meet with them. It is our goal to admit a patient as soon as possible after being referred.

The patient and family make the ultimate decision regarding acceptance of hospice care.

The following information will be requested when Hospice staff take a referral:

- * Patient's name, address, phone number, social security number and date of birth.
- * Diagnosis and prognosis.
- * Medical history, especially information that is helpful in verifying prognosis.
- * Name and telephone number of caregiver, if any.
- * Type of insurance and identification numbers.
- * The name of any home health agency presently involved in providing care, if applicable.

By electing hospice, the patient/family recognize that the focus of care changes from an aggressive course of treatment to one that focuses on the comfort of the patient.

Services provided by hospice are most beneficial if initiated at the time when prognosis is approximately six months. While no client meeting hospice criteria is ever turned away, "brink of death admissions" (where the patient dies 1-3 days after admission) provide the least benefit to the patient/family.

How Can Hospice Benefit the Attending Physician?

The attending physician continues to direct the medical care of the patient once admitted to the hospice program. Through communication with the hospice nursing staff, the attending physician can manage most medical problems while the patient remains at home.

Hospice saves the physician valuable time. Nurses, highly skilled in symptom management and control, complete detailed assessments, and provide the attending physician with information regarding physical condition, change of status, presence of symptoms, and current medications. Physicians

receive updates periodically on their patients, as well as notification of newly arising needs or changes in condition. This allows for prompt intervention to maintain the patient's comfort.

The attending physician can bill Medicare, Medicaid, or insurance carriers for evaluation and medical management services provided in the office, hospital or home. These sources are billed in the usual manner for care given. Medicare is billed with the normal CPT/HCPCS using a **GV** modifier. Consulting physicians must bill **United Hospice of Rockland, Inc.** when providing services **related** to the terminal illness. When providing services **NOT** related to the terminal illness, the physician should bill the insurance company directly but use the **GW** modifier along with the CPT/HCPCS code.

When another physician covers for the designated attending physician, the services of the substituting physician are billed by the designated physician under the reciprocal or locum tenens billing instructions. In such instances, the attending physician bills using the GV modifier in conjunction with either the Q5 or Q6 modifier.

How to Bill For Care Plan Oversight (CPT G0182)

In addition, Medicare allows for reimbursement of the primary physician for overseeing the Hospice Plan of Care. Oncologists, internists, primary care physicians and other specialists, if they are the primary physicians managing the hospice patient are entitled to bill monthly for care plan oversight (CPT CODE G0182). The physician must spend 15 minutes or more in a calendar month interacting with hospice staff related to care plan oversight. Physicians bill Medicare directly for these charges.

According to CPT guidelines, the time doesn't have to be continuous, but can be accumulated throughout the month. This time can include telephone calls between the MD and other professionals involved in the patient's care, review of findings or reports, medical orders and review of care plan.

Only the physician's activities count toward the total time. Additional requirements by Medicare include that the physician: (a) must have personally seen the patient during the prior six months (b) is the primary attending, and (c) has no financial or contractual relation with the hospice.

The documentation required for the physician to bill includes:

1. The approximate number of minutes involved in oversight care.
2. An entry or progress note in the chart describing the status of the patient.
3. Timely signing of written hospice orders, with a copy being filed in the patient's chart.

Hospice Care Remains Underutilized

Hospice is available and accessible to those who need our services. Medicare and most third-party health insurance benefits cover hospice care. Unfortunately, hospice remains an underutilized resource of care and comfort. 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. 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 hospice and focus on living while dying.

Quotable

“Patients want physicians who will share their humanity with them. They want someone who will listen and show they care, even in the face of death. Making an impact on the quality of life or bringing peace to a distraught family is very gratifying.”

*~ John W. Finn, MD
Medical Director,
Hospice of Michigan, Southfield*

Relationship Between Attending Physician and United Hospice of Rockland

GOAL:

The attending physician coordinates hospice care in collaboration with the interdisciplinary team.

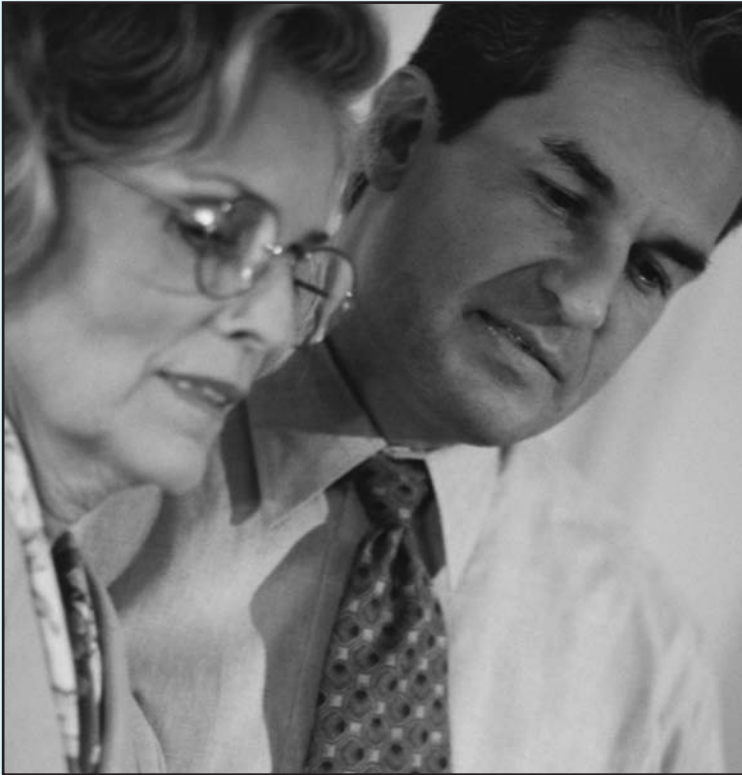
United Hospice of Rockland will:

- * Notify physician of the hospice admission.
- * Forward the initial MD orders for approval and signature.
- * Collaborate with physician regarding changing patient care goals as patient's condition progresses.
- * Inform physician of responsibilities for medical management within the realm of hospice care.
- * The United Hospice of Rockland Medical Director will cover in the absence of the primary physician if the patient is in need of medical intervention.

Attending physician will:

- * Provide admitting diagnosis and prognosis, relevant medical findings, medication and treatment orders, and other pertinent orders regarding the patient's condition.
- * Certify the patient at admission as appropriate for hospice care (life expectancy is six months or less if disease runs a normal progression).
- * Assure continuity of care. The attending physician or designee will be available 24 hours a day, 7 days a week for medical consultation with United Hospice of Rockland.
- * Contact the patient's primary hospice nurse to relay orders and discuss changes in the patient's condition on the day that related services are rendered to the hospice patient.
- * Approve and sign the initial plan of care and standing orders as appropriate for the individual patient and return to United Hospice of Rockland within 7 days of order.
- * Sign death certificate. (Hospice nurse will notify you of your patient's death).

Chapter Two



Communication
at the End-of-Life

Leading the Way in End-of-Life Discussions

Good communication among physicians, patients and their family members is the cornerstone of providing appropriate end-of-life care for patients. Good communication also helps to facilitate 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 treatment responses. Family members note the effects of illness on their loved one.

It is like the elephant in the 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 and the benefits and burdens of possible therapies. They also need to know what might be expected as death approaches.

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 interdisciplinary care team-including the patient, family, physician and hospice staff-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 about the patient's condition should be addressed.

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.

Introducing Hospice Care to Your Patients

Talking to your patient about hospice care can be a delicate undertaking. Listed below are a few suggestions for delivering 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 or telephone call in a day or two to allow the patient and family members to absorb information and ask any additional questions.

Communicate as a Team

Dying is best faced as a team: patient, family, physician and the hospice interdisciplinary team. 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 and with others. It also includes addressing old personal and interpersonal issues and disagreements; and giving and receiving forgiveness and blessings.

Communicating Prognosis

Patients have various motivations 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.")
- * 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 Chapter 5.

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.

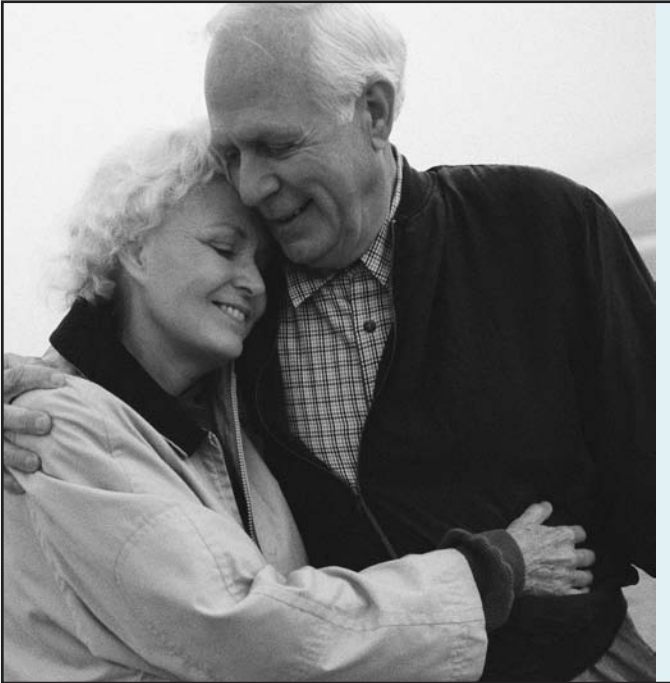
ABCD suggests that the next time you meet with a very sick patient and his or her family, try making at least two or three of these seven promises to them:

- * You will receive the best of medical treatment.
- * We will make every effort to keep you free from 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. 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 Health Care Managers and Clinicians" Excerpts from both books can be read at the ABCD's web site.

Chapter Three



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.

Five Principles of Palliative Care

United Hospice of Rockland 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. These principles may seem like common sense. However, when taken together, they provide a new and more complete way to look at end-of-life 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.

Making the Transition from Cure to Comfort

Identifying when to stop curative care and focus solely on comfort care is perhaps the most difficult aspect of treating a terminally ill patient. Two fundamental facts ensure that the transition to death will remain difficult for some patients: the widespread and deeply held desire to avoid death, and medicine's inability to precisely predict when death will occur.

Patients facing a life-threatening illness have different responses. Some may be willing to pay a high price in quality of life to live a few days or a few weeks longer. Others will not. Many other factors, such as cultural values or family dynamics, may affect how a patient decides to make the transition to dying. Patients with severe cognitive impairment may present additional and unique challenges.

Americans for Better Care of the Dying (ABCD) suggests that physicians ask themselves as they see patients, "Would I be surprised if this patient died this year?" For those "sick enough to die", learn about the patient's concerns. These concerns often can be addressed by a combination of symptom relief, family support, continuity of care, advance planning and spiritual care.

ABCD suggests a physician next might ask, "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?" Use the answers to help develop a care plan that reflects the patient's concerns.

The transition to dying is rarely simple. A patient may refuse definitive treatment such as surgery or chemotherapy, but as the illness progresses, decisions need to be made about accepting other treatments such as transfusions, antibiotics, feeding tubes and attempted cardiopulmonary resuscitation.

For more information about palliative care, see the web sites listed at the end of Chapter 4.

Chapter Four



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 the late 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 seriously ill patients. The cancer pain guidelines developed by the Agency for Healthcare Research and Quality, available at www.ahrq.gov, can be used for managing cancer pain as well as pain in other advanced 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, individual counseling and family counseling can be an additional source of comfort for seriously 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. New national standards 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

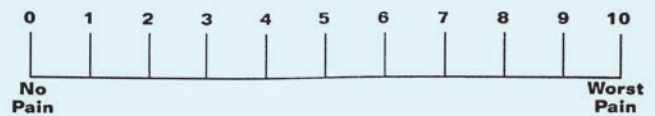
imaginable. Scales that use pictures of faces can help children or those with a language barrier communicate the severity of pain. Pain scales also help evaluate success of pain treatment. Two examples are below.

Pain Scales

Visual Analog Scale - Faces



Numeric Pain Intensity Scale



Other Dimensions of Pain

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

1. Severity: Use pain scales.
2. Quality: Is it dull, sharp, pressing, aching, burning, etc.?
3. Location: Is it deep inside or close to the skin? Does it stay in one place or spread?
4. 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?
5. What brings it on? Makes it worse? Helps relieve it?
6. 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 their spiritual or existential distress that needs attention? 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: 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 seriously ill patients.

Pain Relief

Opioid medications are the cornerstone of pain relief for patients facing advanced illnesses. Unfortunately, many myths about opioid use have stood in the way of appropriate therapy. Non-opioid 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.
- * Fear of side effects of addiction, tolerance and physical dependence.
- * Physicians' fear of governmental regulations related to prescribing opioids.
- * Inadequate insurance coverage or access to medical care for some patients and families.

Quotable

“High quality comprehensive care of all patients - including infants children and adults - at the end-of-life involves the provision of pain management principals that are well established. We, as physicians, have enough medical power and knowledge to relieve all physical suffering. The ability to provide physical relief exists for all patients with safe, effective, reasonable agents. Combining pain management with psychological, interpersonal and spiritual modalities provides for the overall well-being for the patient and their family.”

*~Jeanne G. Lewandowski, MD
Medical Director of Pediatrics
Bon Secours Cottage Health Service,
Grosse Point*

Myths About the Use of Opioids to Control Pain

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

FACT: If a patient has moderate to severe pain, 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: The parenteral use of morphine is more effective than oral.

FACT: Morphine and other opioids are very effective when taken orally. Fentanyl also may be administered transdermally through a skin patch (when patients cannot take medications). 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. Disease progression and tolerance may require an increase or change in the opioids.

MYTH: Opioid medications should be prescribed on an as needed basis.

FACT: Controlling chronic pain requires different interventions than controlling acute pain. Pain relievers are most effective when pain is kept under continuous control by scheduled doses. An as needed schedule 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.

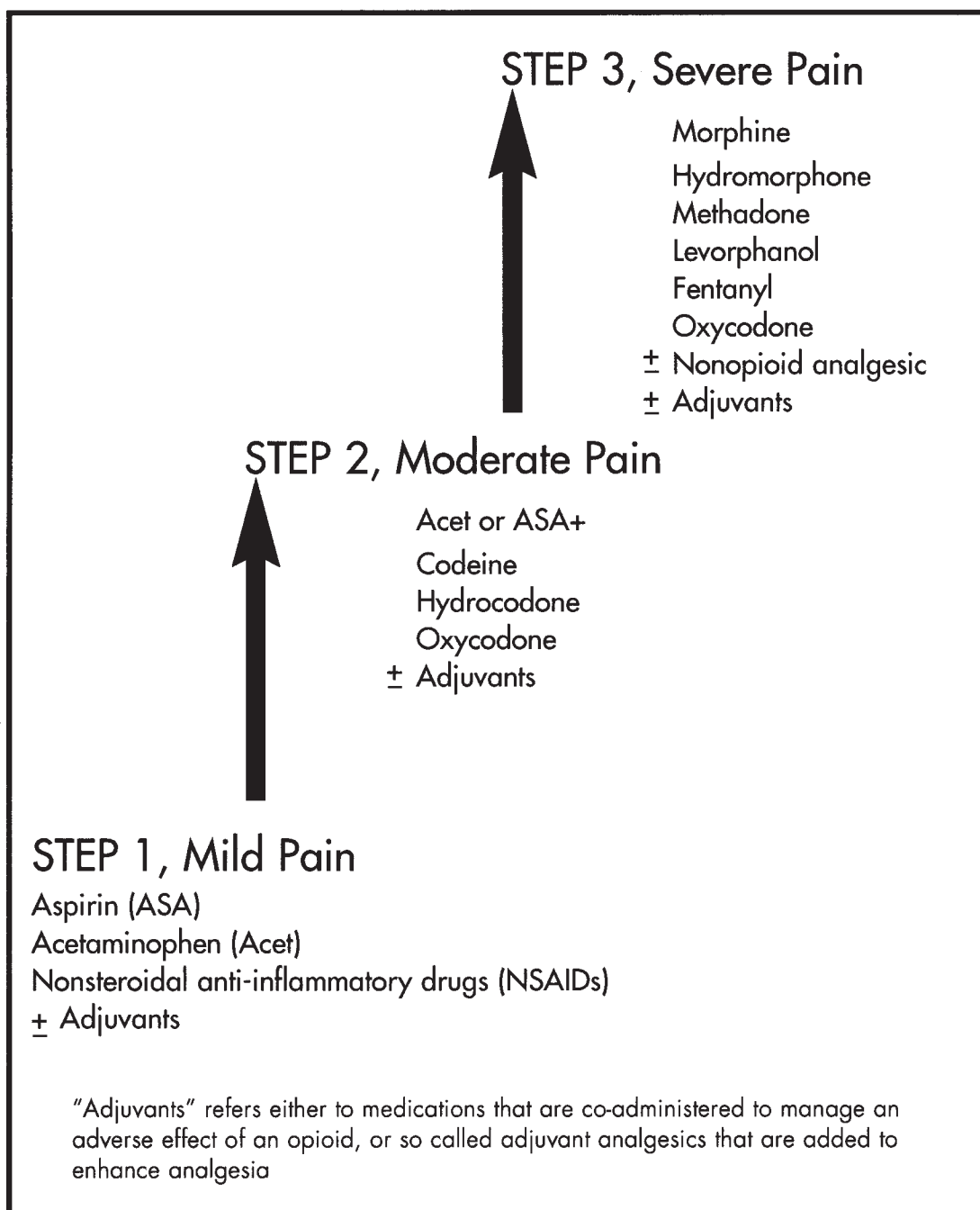
MYTH: Opioid medications will relieve all pain.

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.

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 End-of-Life Care (EPEC) Project's Version of the World Health Organization's Three-Step Ladder for Management of Pain.



Managing Symptoms Other Than Pain

Managing pain is often the main goal of physical care for patients at the end of life. Many patients also suffer from other distressing physical symptoms that may be even more challenging to relieve than pain. A physician should assess these symptoms on an ongoing basis 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, 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, due to heart failure, infection or fluid collection, they may be improved by specific medical treatment. Even when specific treatments cannot be identified or are not effective, relief can be provided in most cases. Opioids are very effective in treating breathlessness in most patients. Sedatives also may be considered, particularly for relief of anxiety associated with breathlessness. Oxygen may be helpful for some patients.

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 is also 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. To the extent possible, encourage eating more bulk producing foods and dietary fiber supplements.

Encourage physical activity and drinking more fluids. Many patients at the end of life, however, need more aggressive management. Regular use of stimulant or osmotic laxatives, along with stool softeners when needed, will manage most patients. Hospice provides physicians with a bowel regime that is very effective.

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 can also contribute to fatigue, and adjustments to the dose may be helpful. The underlying role of the disease should be clarified to the patient and the family.

Symptoms of fatigue and weakness are not easily treated with medications, but some patients may benefit from corticosteroids and psychostimulants. Identify ways to promote energy conservation.

Nausea and Vomiting

At the end of life, many patients lose interest in eating. They may also 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.

The UHR Comfort Pak

With a physician's order, we will place a box of medications in the home to relieve symptoms as they arise. This allows us to control symptoms quickly, especially in the middle of the night. Medications in the Comfort Pak are designed to address those symptoms your patient is most likely to experience. They may include medications such as Compazine suppositories/tablets, Hyoscamine for pulmonary congestion, Haldol for restlessness, Ativan for anxiety or agitation, Morphine liquid for pain or dyspnea, Acetaminophen suppositories for mild pain or fever and ABHR Suppositories (Ativan, Benadryl, Haldol and Reglan). The ABHR is specially compounded by our palliative care pharmacy.

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 lose weight, especially since many cultures strongly associate so much meaning regarding love and nurturing to the act of feeding.

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

Artificial nutrition and hydration are not always beneficial and can create unintended side effects such as fluid overload leading to respiratory distress. These type of interventions can also make management of the patient more difficult for the family in the home setting. These issues should be reviewed with the patient before these interventions are started. If a patient no longer has the capacity to make his/her own decisions, it should be determined if the patient completed any advance directives which can provide guidance as to their wishes. Any discussions that a physician may have had with the patient about their goals of care may provide the physician with additional insight into the patient's wishes.

Emotional and Cognitive Symptoms

Patients often have psychic suffering, and treatment is delayed due to the condition not being recognized. Treatment should start **NO MATTER HOW LONG THE PATIENT MAY LIVE**. Symptoms generally fall into four categories: cognitive (perception and memory), mood (sadness and anxiety), perceptual disturbances (hallucinations and delusions) and behavior (agitation, withdrawal and belligerence). Ninety percent (90%) of terminally ill patients suffer delirium, which is a constellation of cognitive, behavioral and psychological abnormalities associated with transient or permanent dysfunction of the brain. Delusions can be caused by drugs, infection, metabolic disorders, anemia, fluid and electrolyte imbalance, metastasis of the central nervous system, nutritional deficiencies, cerebral

vascular disorders and hepatic, renal or lung organ failure. As a result of these problems, a syndrome known as terminal agitation or restlessness occurs in the actively dying patient and Haloperidol in tablet or a concentrated liquid form of 2mg/ml is often very effective. Severe depression occurs in approximately twenty percent (20%) of patients. This is manifested by a prominent irritable or sad mood disturbance, loss of pleasure in life (anhedonia), decreased energy and concentration, decreased appetite and sleep, withdrawal, agitation, hopelessness and helplessness. They may have suicidal ideation. Selective Serotonin Reuptake Inhibitors (SSRIs), such as Zoloft and Prozac are helpful. Central nervous system stimulants such as Ritalin can be used together with the SSRI's for a quick and safe effect. Tricyclic antidepressants such as Elavil, Pamelor, Norpramin and Sinequan are also used with good results. For certain patients, Remeron and Desyrel, which are in the tetracyclic antidepressant family, may provide relief from depression. For anxiety and agitation, the benzodiazepenes such as Ativan and Xanax provide comfort. The hospice team can assist the patient and family by monitoring the effectiveness of the interventions and by providing reassurance and support. Attention to spiritual concerns is also very important.

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.

Additional resources on pain management and palliative care have been provided for you in the bibliography at the end of this chapter.

Pain Management and Palliative Care Resources

Web Sites:

www.aspi.wise.edu - A network of state based pain initiative organizations composed of nurses, physicians, pharmacists social workers, clergy and government.

www.ampainsoc.org - The American Pain Society, (847) 375-4715 - a multidisciplinary educational and scientific organization dedicated to serving people in pain.

www.cancer.gov - National Cancer Institute 1-800-4CANCER - most recent cancer information from the National Cancer Institute.

www.epec.net - The Education in Palliative and End-of- Life Care (EPEC) Project - is designed to educate physicians around the country on the essential clinical competencies in end-of-life care.

www.guidelines.gov - National Guidelines Clearinghouse - evidence-based clinical guidelines and related abstracts, summaries and comparison materials for health care professionals, sponsored by the Agency for Healthcare Research and Quality; in partnership with the American Medical Association and American association of Health Plans. Includes the AHCPR Cancer Pain Guidelines.

www.painandhealth.org - The Mayday Pain Project - is set up to be an index with links to other sites and resources.

www.eperc.mcw.edu - End of Life/Palliative Education Resource Center (EPEC) - educational materials and information about end of life issues.

www.aahpm.org - American Academy of Hospice and Palliative Medicine.

www.painmed.org - American Academy of Pain Medicine - provides information on quality care for patients suffering from pain.

www.who.int - World Health Organization - information sources, health topics, reports, governance.

Books/Articles

* **Cancer Pain Management**

Fisch M., Burton A. 2007

* **Principles and Practice of Palliative Care and Supportive Oncology**

Berger A., Shuster, J., Von Roenn, J. 2007

* **Oxford Textbook of Palliative Medicine,**

2nd ed. Doyle D., Hanks GWC, MacDonald N., 1998

* **A Physician's Guide to Pain and Symptom Management in Cancer Patients**

Abrahm, J. 2005

* **"UNIPAC SERIES: Hospice/palliative Care Training for Physicians:**

• 48 CME Credits

- The Hospice/Palliative Medicine Approach to End of Life Care
- Alleviating Psychological and Spiritual Pain in the Terminally Ill
- Assessment and Treatment of pain in the Terminally Ill
- Management of Selected Non-Pain symptoms in the Terminally Ill
- Caring for the Terminally Ill-Communication and the Physician's Role on the Interdisciplinary Team
- Ethical and Legal Decision Making When Caring for the Terminally Ill
- The Hospice/Palliative Medicine Approach to Caring for Pediatric Patients
- The Hospice/Palliative Medicine Approach to Caring for Patients with HIV/AIDS

Chapter Five



Advanced 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 their own 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 when caring for a patient who is dying.

What is a Health Care Proxy?

A health care proxy is a document created by a person ("the principal") that names another person as his or her "health care agent" to have the authority to make decisions if and when the principal is determined to be incapable of making medical decisions for him/her self.

All capacitated adults (those without mental impairments) are capable of creating a health care proxy. A person does not need to have the capability of making and understanding all medical decisions in order to be able to issue a health care proxy.

In New York State, a form has been developed by the Department of Health, which can be used. (See the end of this chapter for a copy of the form and feel free to make copies for use in your office.) An individual can develop their own form but it must meet several requirements: (1) it must be signed and dated by the person. (2) It must be signed and witnessed by at least two people at least 18 years of age. The person who is appointed as an agent or an alternate agent CANNOT sign as a witness.

In NYS, an agent has the authority to make any and all decisions on the individual's behalf, EXCEPT in the areas of artificial nutrition and hydration. The agent must have knowledge of the principal's wishes regarding nutrition and hydration. This knowledge does not have to be in writing. The law refers to it as "reasonable knowledge".

A physician who is providing medical care to an individual cannot serve as their health care agent. Physicians must honor the wishes of a health care agent in the same way that they would have to honor the wishes expressed by a patient.

Living Wills

A living will is a document that provides specific instructions about health care treatment. It is generally used to state one's wishes to refuse life-sustaining treatment under specific circumstances, i.e., terminal illness, permanent vegetative state, and irreversible illness. It does not appoint a health care agent. There is no statutory law in New York that recognizes a living will. However, this document is recognized by the highest courts in New York State as clear and convincing evidence of a patient's wishes.

Introducing the Topic of Advance Care Planning to Your Patients

Research has shown that patients expect physicians to introduce the topic of advanced care planning. The following steps should be taken to ease the discussion:

1. Make it a routine process with every adult 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 as outlined earlier and have forms available. (A copy of the NYS proxy form has been included at the end of this chapter.)
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 decisions.

Reviewing Your Patient's Wishes

If you are aware that a patient has made decisions about his or her future care planning, it is important for the physician, patient and health care agent to review the patient's wishes. This is your opportunity to correct inconsistencies or clear up misunderstandings.

After a health care proxy has been completed, the patient should give you a copy of the signed document to place in their medical record. Encourage your patient to keep duplicates as well as the original signed document with other important papers. Tell him or her to give copies to the person he/she selected as the health care agent. If the patient is being treated at a health care facility, a copy of the document should be filed there as well.

Make sure that you assure your patients that their wishes will be honored if they become unable to communicate their own decisions, and they will be kept as comfortable and pain free as possible.

Hospice and Advance Directives

Hospice does not require that patients complete advance directives (including DNR) to be admitted to the program. Upon admission, the hospice team will inquire as to the existence of advanced directives. Information about advance directives will be provided by to all patients and families and patients will be encouraged to complete advance directives. With our support, the majority of hospice patients who have capacity to do so usually complete advance directives at some point.

www.Assuringyourwishes.org

This is a free service created and operated by UHR. It is a secure on-line service that enables individuals to store and retrieve their advance directives. It also allows physicians who are registered with the site to search for their patients' directives.

You can register by going to the site and clicking on the black box that says, "Click Here to Search Advance Directives". You will see where non-registered physicians can register. Encourage your patients to complete their directives and store them with www.Assuringyourwishes.org

Please note that we have provided you with copies of a health care proxy form, a NYS Living Will, a Non-Hospital DNR order and an authorization form for [Assuringyourwishes.org](http://www.Assuringyourwishes.org). Please make copies to distribute to your patients.

We gratefully acknowledge the Michigan State Medical Society for allowing us to reprint information from The Michigan Physician Guide to End of Life Care.

Health Care Proxy

(1) I, _____

hereby appoint _____
(name, home address and telephone number)

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise. This proxy shall take effect only when and if I become unable to make my own health care decision.

(2) **Optional: Alternate Agent**

If the person I appoint is unable, unwilling or unavailable to act as my health care agent, I hereby

appoint _____
(Name, home address, and telephone number)

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise.

(3) Unless I revoke it or state an expiration date or circumstances under which it will expire, this proxy shall remain in effect indefinitely. (Optional: If you want this proxy to expire, state the date or conditions here.) This proxy shall expire (specify date or conditions): _____

(4) **Optional:** I direct my health care agent to make health care decisions according to my wishes and limitations, as he or she knows or as state below. (If you want to limit your agent's authority to make health care decisions for you or to give specific instructions, you may state your wishes or limitations here.) I direct my health care agent to make health care decisions in accordance with the following limitations under instructions (attach additional pages as necessary): _____

In order for your agent to make health care decisions for you about artificial nutrition and hydration (nourishment and water provided by feeding tube and intravenous line), your agent must reasonably know your wishes. You can either tell your agent what your wishes are or include them in this section. See instructions for sample language that you could use if you choose to include your wishes on this form, including your wishes about artificial nutrition and hydration

(5) Your Identification *(please print)*

Your Name _____

Your Signature _____ Date: _____

Your Address _____

(6) Optional Organ and/or Tissue Donation

I hereby make an anatomical gift, to be effective upon my death, of:

(check any that apply)

Any needed organs and/or tissues

The following organs and/or tissues _____

Limitations: _____

If you do not state your wishes or instructions about organ donation on this form, it will not be taken to mean that you do not wish to make a donation or prevent a person, who is otherwise authorized by law, to consent to a donation on your behalf.

Your Signature _____ Date _____

(7) Statement by Witnesses: *(Witnesses must be 18 years of age or older and cannot be the health care agent or alternate.)*

I declare that the person who signed this document is personally known to me and appears to be of sound mind and acting of his or her own free will. He or she signed (or asked another to sign for him or her) this document in my presence.

Date _____ Date _____

Name of Witness 1 (print) _____ Name of Witness 2 (print) _____

Signature _____ Signature _____

Address _____ Address _____

NEW YORK LIVING WILL

This Living Will has been prepared to conform to the law in the State of New York., as set forth in the case *In re Westchester County Medical Center*, 72 N.Y. 2d 517 (1988). In that case the Court established the need for “clear and convincing” evidence of a patient’s wishes and stated that the “Ideal situation is one in which the patient’s wishes were expressed in some form of writing, perhaps a “Living Will.”

I, _____, being of sound
(print your name)

mind, make this statement as a directive to be followed if I become permanently unable to participate in decisions regarding my medical care. These instructions reflect my firm and settled commitment to decline medical treatment under the circumstances indicated below:

I direct that my attending physician to withhold or withdraw treatment that merely prolongs my dying, if I should be in an incurable or irreversible mental or physical condition with no reasonable expectation of recovery, including but not limited to: (a) a terminal condition in which I am permanently unconscious condition; or (c) a minimally conscious condition in which I am permanently unable to make decisions or express my wishes.

I direct that my treatment be limited to measures to keep me comfortable and to relieve pain, including any pain that might occur by withholding or withdrawing treatment.

While I understand that I am not legally required to be specific about future treatments If I am in the condition(s) described above I feel especially strongly about the following forms of treatment:

- I do not want cardiac resuscitation.
- I do not want mechanical respiration.
- I do not want artificial nutrition and hydration.
- I do not want antibiotics.

Cross out any statements listed above that do not reflect your wishes.

However, I do want maximum pain relief, even if it may hasten my death.

Other directions:

Add personal instructions (if any)

New York Living Will
Page 2 of 2

These directions express my legal right to refuse treatment, under the law of New York. I intend my instructions to be carried out, unless I have rescinded them in a new writing or by clearly indicating that I have changed my mind.

Signed _____ Date _____

Address _____

I declare that the person who signed this document appeared to execute the living will willingly and free from duress. He or she signed (or asked another to sign for him or her) this document in my presence.

Witness _____

Address _____

Witness 2 _____

Address _____

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is proud to be a community resource for end-of-life issues.

State Of New York: Department Of Health

Nonhospital Order Not To Resuscitate

Person's Name _____

DOB: ____/____/____

◆ Do not resuscitate the person named above.

For A Patient Lacking in Capacity,
a 2nd Physician Signature is Required

Physician's Name (Print)

Physician's Name Print

Physician's Signature

Physician's Signature

Physician's License Number

Physician's License Number

Date Signed: ____/____/____

Date Signed: ____/____/____

It is the responsibility of the physician to determine at least every 90 days, whether this order continues to be appropriate, and to indicate this by a note in the patient's medical chart. The issuance of a new form is NOT required, and under the law this order should be considered valid unless it is known that it has been revised. This order remains valid and must be followed, even if it has not been reviewed within the 90 day period.

"In the event of acute cardiac or respiratory arrest (heart or breathing stops) I request that no cardiopulmonary resuscitation be done. I understand that I may revoke this directive at any time. The physician must sign this form before it takes effect."

Patient / Representative / Healthcare Agent

Date Signed: ____/____/____

Witness #1

Date Signed: ____/____/____

Witness #2

Date Signed: ____/____/____



A Service of Assuringyourwishes.org

ASSURINGYOURWISHES.ORG ADVANCE DIRECTIVE AUTHORIZATION FORM

By signing this form, I am requesting that AssuringYourWishes.org make available my most recent advance directive, a copy of which accompanies this Advance Directive Authorization Form, to my health care proxy or alternate healthcare proxy, legal guardian (if applicable) and all health care providers involved in my medical care. I understand that I may change or revoke the advance directive accompanying this form at any time, and that I may also revoke my authorization for AssuringYourWishes.org to post my advance directive at any time. I agree to notify AssuringYourWishes.org of any such change or revocation in writing. If I revoke my advance directive or I revoke my authorization for AssuringYourWishes.org to post my advance directive, my advance directive will be removed from the AssuringYourWishes.org website. If I change my advance directive, I agree to submit a new Advance Directive Authorization Form and a copy of my new advance directive to AssuringYourWishes.org. The new advance directive will then be posted on the AssuringYourWishes.org website, and the old advance directive will be removed. I agree that AssuringYourWishes.org will not be held responsible for the release of my advance directive information in accordance with the terms agreed to, prior to AssuringYourWishes.org's receipt of written notification of a change to my advance directive, or a revocation of my advance directive or revocation of my authorization for AssuringYourWishes.org to post my advance directive.

I understand that I will receive three (3) AssuringYourWishes.org identification cards with my name and password listed. I understand that my health care proxy or alternate healthcare proxy, legal guardian (if applicable) and all health care providers involved in my medical care will be granted access to my advance directive when medically necessary, and only those individuals to whom I have given my password will be able to access my advance directive. I understand that additional information regarding the Advance Directive Deposit program, including the privacy and security policy of AssuringYourWishes.org is available on the AssuringYourWishes.org website.

While AssuringYourWishes.org attempts to provide reliable posting services for your Advance Directive, occasionally circumstances beyond our control interfere with the internet connectivity or server stability where the Advance Directives are posted. Therefore, you acknowledge and agree that the posting of the Advance Directive as a free Service, is provided AS IS and AS AVAILABLE, without warranty of any kind.

AssuringYourWishes.org EXPRESSLY DISCLAIMS ANY AND ALL WARRANTIES OF ANY KIND, WHETHER EXPRESS OR IMPLIED, INCLUDING, BUT NOT LIMITED TO: (A) ANY WARRANTIES AS TO THE AVAILABILITY, ACCURACY, COMPLETENESS, CURRENTNESS, VALIDITY, EFFECTIVENESS OR RELIABILITY OF THE POSTED ADVANCE DIRECTIVE AVAILABLE THROUGH THE SERVICE, OR THE SERVICE ITSELF; (B) ANY WARRANTIES THAT THE SERVICE WILL BE UNINTERRUPTED, TIMELY, SECURE, OR ERROR FREE, OR THAT SOFTWARE DEFECTS WILL BE CORRECTED; AND (C) FITNESS FOR A PARTICULAR PURPOSE. NO ADVICE OR INFORMATION, WHETHER ORAL OR WRITTEN, OBTAINED BY YOU FROM AssuringYourWishes.org OR THROUGH THE SERVICE SHALL CREATE ANY WARRANTY NOT EXPRESSLY MADE HEREIN.

Name _____ Date of Birth _____

Mailing Address _____

City: _____ State _____ Zip _____

Phone Number _____ E-mail: _____

Signature _____ Date: _____

Note: If the individual signing this form is not the same as the person whose name is listed on the advance directive, print the name of the individual signing the form, and indicate whether the individual is the named person's health care proxy, alternate health care proxy or legally appointed guardian. Please also provide proof of the authorization to act on behalf of the named person.

Print Name

Authority to Act on Behalf of the Named Person

Please mail to: Assuring Your Wishes.Org C/O United Hospice of Rockland, Inc., 11 Stokum Lane, New City, NY 10956