



Hospice Care

A Physician's Guide

*Includes Medical Guidelines
for Determining Prognosis*



MICHIGAN HOSPICE
& PALLIATIVE CARE ORGANIZATION

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Lansing, Michigan 48917



MICHIGAN HOSPICE & PALLIATIVE CARE ORGANIZATION

HOSPICE CARE: A PHYSICIAN'S GUIDE

This reference guide was first published by the Minnesota Hospice Organization, and contained information specific to hospice programs in Minnesota as well as data specific to hospice care, regardless of where delivered. Because of the extraordinary generosity of the Minnesota group, and with the able assistance of the National Hospice & Palliative Care Organization, Michigan was able to obtain the rights to modify the guide for Michigan use, and publish a Michigan version.

This reference guide is designed to help physicians and other referral sources use hospice in the treatment of terminally ill patients. Materials were prepared with the help and input of hospice medical directors and physicians throughout Michigan.

The Michigan Hospice & Palliative Care Organization revised the guide with the able assistance of hospice physicians in Michigan, and this guide contains Michigan-specific information. The Michigan Hospice & Palliative Care Organization is a member-supported organization of hospice programs, businesses, and many individuals that advocate for the needs of the terminally ill and their families, educate professionals and the general public regarding hospice care, and promote increased access to quality hospice care for all Michiganders.

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Forward

by Karen S. Ogle, M.D.

As physicians, we are trained to fight disease and death. We have been taught to diagnose and cure, and prolonging life can often seem like our only mission as health professionals.

But doctors also have a vital role to play when curative treatment has become futile. It is neither to push forward with the use of intrusive and useless technology nor to abandon patients with the resigned observation that “there’s nothing more we can do.” In the last stage of life, the physician can help the dying patient and the patient’s family to live those final days to the fullest.

Through hospice care, physicians can become part of a team that ensures effective management of their patients’ pain and other physical symptoms as well as their broader psychosocial and spiritual needs. No patient need be helpless and alone when facing a terminal illness.

This is sometimes called death with dignity, but in truth what you can give to patients is something larger and more precious: the opportunity to live with dignity at the end of life.

This book is intended as a guide for physicians who are

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ready to accept an expanded role that includes enhancing life even when it can no longer be extended. It will help you to understand the place of hospice in the continuum of medical care and to add the tools of hospice and palliative medicine to your clinical practice.

Physicians who understand what hospice care has to offer can ensure that their patients receive hospice services in the most timely manner. You are the person in whom your patients have entrusted their care, and it is you who can help them find an affirmation of life in the face of death.

Karen S. Ogle, M.D.
Professor, Family Practice
Director, Palliative Care Education and Research Program
Cancer Center
Michigan State University



Physician's Role in Hospice Care

The importance of the physician's relationship with a terminally ill patient and his or her family throughout the course of illness cannot be overemphasized. In a focus group discussion conducted through the Allina Foundation's Project DECIDE, one patient commented, "You are so tied to physicians, you are relying on them for the lifeline. If they suggest an option, you think, OK, I guess I better look at this." Another reiterated the trust relationship: "I just went along with what the doctor said...I thought he knew what to do and would take care of it" (Allina Foundation, 1994).

The physician is a key member of the hospice team. From initiating the discussion about hospice to signing the death certificate, the physician's involvement is crucial to the patient, family and other members of the hospice team. Yet many physicians, especially those who refer to hospice only occasionally, may not be aware of the full range of services offered by hospice or the tremendous growth experience at the end of life that can occur within patients and families.

In addition to the physician, the hospice team includes nurses, home health aides and homemakers, social workers, chaplains, and volunteers. Under the physician's direction, the hospice team specializes in pain and symptom management, and provides support for the family as well as the patient.

Preparing Patients for Hospice Care



Rarely in the course of a patient's disease and treatment is there one moment when the focus clearly shifts from curative to palliative. Just as disease treatment is a process, so is preparing a patient for the time when treatment for cure is no longer an option. Preparing a patient begins with an honest discussion of the disease and its outcomes.

According to Leslie J. Bricker, M.D., Medical Director, Hospices of Henry Ford Health System, Detroit, Michigan. "We need to dispel the notion among health care providers and patients that a referral to hospice implies "giving up". Hospice is goal-oriented but the goals have shifted from cure to symptom control, quality of life, and reconciliation with family; from healing of the body to healing of the spirit. Those of us involved in the care of hospice patients on a daily basis realize that hospice care is truly "intensive care"

In a recent Louis Harris Poll, 96 percent of Americans said they would want to be told if they have cancer and 85 percent would want a "realistic estimate" of how long they had to live if their type of

"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, M.D., Medical Director, Hospice of Michigan.

cancer usually led to death in less than a year.

LISTENING TO PATIENT NEEDS

Introducing a patient to hospice involves more than telling them, "Now it's time for hospice." It is also an art that involves listening to what a patient is saying.

"Patients may be ready for hospice before we realize," says Tom George, M.D., Medical Director for Hospice of Southwestern Michigan and Michigan legislator. "We may have presented a wide range of treatment options - and all the while the patient has been thinking, "I just want to go home and be comfortable."

FEAR OF THE UNKNOWN

For many people, fear of the unknown is at least as great as fear of death itself (Fletcher, 1992). Presenting hospice as a medical option for treating a terminal illness can help with many unknowns - "fear of uncontrollable pain, nausea, vomiting, embarrassment and especially abandonment" - that often accompany end stage disease (Creagan, 1994).

Not all patients are ready to accept the idea of hospice care

Suggestions for delivering difficult news

Following are some 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. Try to avoid the patient being alone to receive difficult news.
- Use plain 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 several times if necessary. Allow time to recognize the patient's emotional reaction.
- Find out and address specific concerns of the patient and family.
- Without overwhelming the patient and family, provide options such as hospice, and to the extent possible, offer a general estimate of length of survival (Creagan, 1994 and Faulkner, 1994).

when it is introduced. Often the barriers to acceptance are less a patient's unwillingness to accept the disease prognosis and more a fear of abandonment.

According to Dr. George, "At this critical time patients are clinging to every word from their doctor. So by saying, "I'll still be your doctor when you're in Hospice; I'll still be thinking of you", we can allay this fear of being abandoned."

WORKING WITH THE FAMILY

The patient's family is crucial in the hospice discussion. A patient can be ready to accept hospice when their family is not. Sometimes they are the ones encouraging the patient to continue treatment even when the burdens outweigh the benefits.

"Families are often concerned about how long their loved one has to live," says Fred Isaacs, M.D., Medical Director for Hospice of Lansing. "I tell them there are no pat answers. No one can 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 to ensure that their final days are comfortable."

Often, the family simply needs to hear that hospice is a choice the patient is making. As the physician, you can best ask the question for the family, "Given the medical information, what do you want?"

Dr. Tom George states, "When we survey hospice patients and their families one of the comments we hear over and over is, "Why couldn't we have come in earlier? Why didn't my doctor tell us about hospice?"

"Hospice is a place of comfort and rest on a difficult journey"

**Susan Urba, M.D.
University of Michigan
Medical Center**

Common Questions From Patients and Families:

Q: Does this mean there's nothing more we can do?

A: Hospice is not an end to treatment — It is a shift to intensive palliative care that focuses on allowing the patient to live his or her life to the fullest. In addition to managing pain, hospice provides extensive counseling and social service support to address the emotional and spiritual aspects of coping with a terminal illness.

Q: What about the pain?

A: A primary goal of hospice is effective pain management. Pain related to the terminal illness is aggressively treated using a wide variety of medically sound therapies.

Q: What should we do next?

A: The next step is to contact a hospice. Here are a few important points to tell your patient about hospice:

- As your physician, I will continue to see you and care for you.
- Our first priority is managing your symptoms.
- Services are available where you live.
- Your family will also receive the support of the hospice team.
- Hospice care is covered by Medicare, the Michigan Medicaid Program, and many private insurances.

Utilizing the Hospice Team



The attending physician is the patient's primary medical doctor, provides medical services throughout the course of the illness, and is an integral part of the hospice team.

HOW TO REFER TO HOSPICE

An initial referral to hospice always begins with an honest discussion with the patient about care and treatment options.

Once this has occurred, a hospice program will ask for the following information regarding the patient:

- admitting diagnosis and prognosis
- current medical findings
- orders for medications and treatments
- patient and family understanding of disease and prognosis
- relevant patient and family information
- history and physical
- order for hospice care

“The key to success at hospice is the team concept. The team concept provides much greater support than any one discipline could ever provide. It takes the physician and all the hospice staff to deliver quality of life at this time.”

**Fred Isaacs, M.D.
Internal Medicine**

ONGOING CARE

Once the patient is enrolled in a hospice program, the attending physician will be a primary resource on the patient's medical condition and needs. The hospice nurse will be in regular contact regarding symptom management, changes in the patient's condition, and need for clinic or home visit follow-up.

The physician is responsible for

- signing the initial certification of terminal illness
- reviewing the hospice plan of care for the patient
- ongoing clinic visits with the patient
- prescribing medication for comfort care
- reviewing with hospice staff the patient's condition and prognosis
- making telephone contact and house calls to the patient as necessary
- signing the death certificate
- home visits when necessary

“The goal of medical intervention at this point is to relieve distressing symptoms and to promote a peaceful death. Thus, medical efforts are turned from the disease and its attendant complications, and turned toward patient comfort.”

John W. Finn, M.D.

EXTENDING CARE THROUGH THE HOSPICE TEAM

Because the care needs of a dying patient encompass more than medical treatment of a disease, the hospice team can be a valuable resource in dealing with complex issues and extending the physician's care.

"Most physicians would say hospice care is worth the investment," said Michael Levy, M.D., Ph.D., director of the supportive oncology program at the Fox Chase Cancer Center in Philadelphia. "[In many cases] the doctor doesn't get calls [or] go to the ER in the middle of the night because hospice takes the calls and the hospice nurse goes out to the home."

"The hospice team is skilled at patient and family education," Dr. Levy continues, "so medicines are taken properly and side effects can be anticipated and treated."

The team approach to hospice care can ultimately alleviate much of the stress traditionally associated with care of the dying patients.

According to Ira Byock, M.D., Director of Palliative Medicine at Dartmouth-Hitchcock Medical Center, "Care of the dying stops being a stressor and starts being a source of professional satisfaction" (Skelly, 1994).

MYTH:
Physicians lose control of the plan of care when their patients enter hospice.

FACT:
"Hospice is the missing resource as a patient becomes terminally ill. It is the physician's tool, and under the physician's direction, the team can and does provide the necessary care, for physical, emotional, and spiritual needs . . . for the patient and the family."

Tom M. George,
M.D.

Hospice Interdisciplinary Team

Each team member has a role to play to address the physical, emotional, and spiritual needs of patients and family.

Attending Physician

Patients designate an attending physician to manage their care.

Hospice Medical director

The Medical Director oversees the treatment by the hospice team and coordinates with the Attending Physician.

Hospice Nurse

Hospice Nurses coordinate the individualized care plan and provide specialized palliative care services.

Social Worker

Hospice Social Workers offer emotional support, counseling and community resource support services.



Patient & Family

Spiritual Care

The Hospice Spiritual Care Coordinator assists in identifying spiritual concerns and the connection with a community of faith.

Home Health Aide

Hospice Home Health Aides assist with personal care and light housekeeping services.

Other therapists

Physical, occupational and speech therapists provide palliative care according to the individualized care plan.

Bereavement Coordinator

Bereavement Care supports the person and family throughout the dying process and offers follow-up grief education and support .

Volunteer

Trained Volunteers provide a variety of services, including companionship and respite care.



Where Hospice Care is Provided

Hospice care is available to patients in a variety of settings. While home is the most common and the preferred place for many patients, it is not always possible or even desirable for all hospice patients. Individual patient needs determine the location for delivery of hospice care. Patients can receive the services of the hospice team at home, in the hospital, or in a long-term care or other residential facility.

HOSPICE CARE IN THE HOME

Hospice patients in the home receive regular visits from the interdisciplinary team. In addition, hospice nurses will triage phone calls 24 hours a day from patients and families, communicating with the physician as necessary. Pain, nausea, vomiting and bowel management are special areas of expertise. Hospice nurses can handle many of these issues, using standing orders from the physician. Patients at home can continue to make clinic visits or may receive visits from the physician in the home.

Most hospice patients at home are cared for by family caregivers, but more and more hospice programs are able to offer care to those patients who choose to live alone. In such cases, the hospice team assists in making special arrangements. Check with the hospice to see if this option is available.

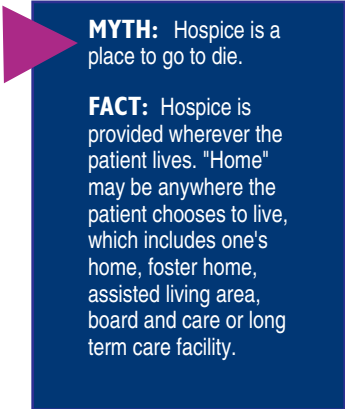
**Nine
out of
ten
Americans
said they
would
prefer to
be cared
for and
die at
home.**

HOSPICE CARE IN THE INPATIENT SETTING

An acute care setting is sometimes necessary for the management of symptoms related to the terminal disease. General inpatient care is available in acute care facilities which contract with the hospice program. These facilities have made arrangements for such things as direct admission of the hospice patient to the unit and waiving of routine tests which may not be appropriate. In addition, the inpatient staff has been oriented to the special needs of the dying patient and grieving family.

The hospice nurse remains case manager for the patient throughout the inpatient stay and communicates with the physician about the patient's care. Other hospice team members make visits to the patient to ensure continuity of care.

Respite care in an inpatient setting is also available for brief periods of time when family members are in need of a rest from caregiving duties. Respite care is covered under the Hospice Medicare Benefit.



MYTH: Hospice is a place to go to die.

FACT: Hospice is provided wherever the patient lives. "Home" may be anywhere the patient chooses to live, which includes one's home, foster home, assisted living area, board and care or long term care facility.

RESIDENTIAL HOSPICE

Home-like, residential facilities exclusively for hospice patients and their families are available in some areas. The hospice team remains in charge of patient care and visits frequently. Payment for residential room and board is usually made privately. The Medicare Hospice Benefit provides coverage for all services related to the terminal illness except room and board.

HOSPICE IN LONG TERM CARE FACILITIES

Palliative care and hospice services are available for individuals living in long term care facilities. Collaborative agreements between hospice programs and long term care facilities make it possible for residents, family and staff to benefit from a unique multi-disciplinary approach to care delivery. The patient and family focus of care provides for innovative delivery of care interventions. Interventions such as pain and symptom management lead to patient acceptance of the dying process, greater patient and family satisfaction of care and improved quality of life.

“Some patients cannot get the care they need at home and end up in a nursing home,” says Dr. Fred Isaacs. “ I think that one of the greatest services we provide is support of these nursing home patients. They are in strange surroundings and they are dying. The hospice team works with the nursing home staff to provide extra support and time and care to make their final days comfortable. The hospice team also supports the nursing home staff as they lose patients they have learned to love.”

Surviving family members and long term care staff receive support through hospice bereavement services for a period of time after the individual’s death. This support leads to healthier expressions of grief and loss, and stress management.

WORKING WITH PHYSICIANS

Hospice program members of the Michigan Hospice and Palliative Care Organization work with Hospice Medical Directors and referring physicians trained in many specialities, and from many Medical Schools. Both MD’s and DO’s are well represented within the hospice community throughout the state, and are prepared to work with all physician specialities in developing the right plan of care for terminally ill patients.



How Hospice Care is Paid For

Hospice programs work closely with patients and families to identify reimbursement options. Care is provided regardless of the patient's ability to pay.

The Medicare Hospice Benefit

Hospice care provided by Medicare certified hospice programs is covered by the Medicare Hospice Benefit (Part A). Physician services can continue to be billed through Medicare Part B.

Medicare beneficiaries who choose hospice care receive non-curative medical and support services for their terminal illness. Home care may be provided along with necessary inpatient care and a variety of services not otherwise covered by Medicare.

ELIGIBILITY FOR CARE

Medicare coverage for hospice care is available if

- the patient is eligible for Medicare Part A;
- the patient's physician and the hospice Medical Director certify that the patient is terminally ill with a life expectancy of six months or less;
- the patient signs a statement choosing hospice care instead of standard Medicare benefits for the terminal illness; and
- the patient receives care from a Medicare-certified hospice program. (Nearly all hospices in Michigan are Medicare-certified.)

LENGTH OF BENEFIT

When a Medicare beneficiary elects to receive hospice care, he or she is entitled to receive that care as long as he or she meets the eligibility criteria. Hospice benefit periods consist of two 90-day benefit periods, followed by an unlimited number of 60-day benefit periods. The benefit periods may be used consecutively or at intervals. The patient must be certified as terminally ill at the beginning of each period.

The Hospice Medicare Benefit periods as stated above became effective with the signing of the Balanced Budget Act of 1997 by President Clinton on August 5, 1997. The change eliminates any lifetime limit to hospice care for Medicare beneficiaries. In addition, a patient who experiences a remission in the terminality of their disease and disenrolls in hospice care, can be eligible for hospice care again in the future without regard to previous use of hospice services.

Medicaid requires that recertification of the terminal illness occur at the beginning of each Medicare-defined benefit period. Medicaid patients are also required to have a terminal prognosis of six months or less.

SERVICES NOT COVERED

All services required for the management of the terminal illness must be provided by or through the hospice. When a Medicare beneficiary chooses hospice care, Medicare will *not* pay for

- active treatment of the terminal illness that is not for symptom management and pain control
- care provided by another hospice that was not arranged by the patient's hospice
- care from another provider that duplicates care the hospice is required to furnish

AVAILABILITY OF OTHER MEDICARE BENEFITS

When a Medicare beneficiary chooses hospice care, he or she gives up the right to standard Medicare benefits for the management of the terminal illness. A patient can use all appropriate Medicare Part A and B benefits for the treatment of health problems unrelated to the terminal illness (U.S. Department of Health & Human Services Health Care Financing Administration, 1995).



Benefits covered by Medicare under the Hospice Benefit

The Hospice Medicare Benefit covers the following services:

- ✓ Physician services
- ✓ Nursing care
- ✓ Medical equipment
- ✓ Medical supplies
- ✓ Outpatient drugs for symptom management and pain relief
- ✓ Short-term inpatient care, including respite care
- ✓ Home health aide and homemaker services
- ✓ Physical and occupational therapy
- ✓ Speech/language pathology services
- ✓ Medical social services
- ✓ Dietary and other counseling

Medicare pays for the entire cost of these services. However, hospices have the option of charging their patients a 5% coinsurance amount for drugs (up to a \$5 maximum per drug) and 5% coinsurance on inpatient respite care (up to an amount equal to the annual Part A inpatient deductible) (Health Care Financing Administration, 1995).

Reimbursement for Physicians under Medicare

The attending physician is the physician designated by the patient to have the most significant role in his or her care. The attending physician continues to bill Medicare Part B for professional services — home, inpatient, or nursing home visits — in the usual manner, independent of the Hospice benefit. Medications, laboratory tests, and other non-physician services required for the management of the terminal illness are paid for by the hospice program through the hospice benefit.

Attending physicians can bill for care plan oversight for hospice patients. Payment is available for one physician per month for oversight supervision involving 30 or more minutes of the physician's time per month.

Care plan oversight includes the following physician activities:

- development/revision of care plans
- review of subsequent reports of patient status and related laboratory studies
- coordination and communication (including the telephone calls) with other health care professionals involved in the patient's care (excluding telephone calls to patients and family members)
- adjustment and integration of medical treatments.

MYTH: Physicians will lose income

FACT: While hospice's home-care focus and interdisciplinary team involvement can potentially reduce the number of physician office visits and hospital stays, attending physicians can bill Medicare and other carriers for regular visits related to the hospice care plan.

Physician Billing Guidelines for Medicare

This table reflects the provision of care and services related to the terminal illness covered by the Hospice Medicare Benefit.

| DESCRIPTION | BILL MEDICARE | BILL HOSPICE* | BILL HOSPICE |
|--|----------------|---------------------------|-------------------------------|
| | PART B | INTERMEDIARY PAYS HOSPICE | COVERED UNDER HOSPICE BENEFIT |
| ATTENDING PHYSICIAN Professional Fee | ✓ | | |
| COVERING (Stand in) PHYSICIAN Professional Fee | | ✓ | |
| CONSULTING PHYSICIAN Professional Fee | | ✓ | |
| X-RAYS Technical Component | | | ✓ |
| X-RAYS Physician Component | ✓ attending | ✓ consulting | |
| RADIATION THERAPY Technical Component | | | ✓ |
| RADIATION THERAPY Physician Component | ✓ attending | ✓ consulting | |
| LABS | | | ✓ |
| CHEMOTHERAPY | | | ✓ |
| PRESCRIPTION MEDICATIONS | | | ✓ |

* The Medicare intermediary pays the hospice an amount equivalent to 100% of allowable charges for those physician services furnished under arrangements with the hospice. Payment is then provided to the physician by the hospice. Billing through hospice is required when the patient is covered by the Hospice Medicare Benefit. A written agreement between the Hospice and the covering (stand in) or consulting physician is needed.

Attending Physician is the physician designated by the patient to have the most significant role in the determinations and delivery of the individual's medical care.
Bill Medicare Part B.

Covering Physician is the physician who sees the patient on behalf of the Attending Physician as part of vacation coverage or on-call status.
Bill Hospice using HCFA 1500.

Consulting Physician is the physician who provides direct patient care to a hospice patient for a condition related to the terminal illness.
Bill Hospice using HCFA 1500.

Adapted with permission from Hope Hospice

Other Payer Sources

HOSPICE MEDICAID BENEFIT

The Michigan Medicaid Hospice Benefit generally follows the Medicare Hospice Benefit, with recertification required according to Medicare benefit periods.

PRIVATE INSURANCE COVERAGE

The majority of commercial insurance providers cover hospice care either through a specific hospice benefit or through a home care benefit. Several providers have recently developed or are developing hospice benefits that reimburse on a per diem basis (like Medicare). When there is no specific hospice benefit, insurance companies often reimburse through a home health care benefit. Patients should be encouraged to contact their insurance carrier about coverage for hospice.

NON-MEDICARE-CERTIFIED HOSPICE PROGRAMS

Services from hospices that are not Medicare certified can be billed under regular Medicare Part A. Many of the hospice services are provided free of charge, and the patient can access grants to cover billable services.

MYTH: Medicare and Medicaid patients can only receive hospice care for six months

FACT: The patient's condition is reviewed whenever medically necessary (e.g., a change in their medical condition) but at a minimum must be reviewed at the end of each benefit period. These reviews must continue after all benefit periods, regardless of the number of benefit periods used. If the patient's condition stabilizes at any point during the hospice care, the patient may be discharged from hospice. However, the patient can be readmitted later if their medical condition again meets eligibility requirements for hospice care. If the patient is discharged from hospice in any benefit period, they will be eligible for further hospice care under the new legislation for the Medicare Hospice Benefit, which allows for two 90-day benefit periods, followed by an unlimited number of 60-day benefit periods.

For More Information



ABOUT HOSPICE OR REFERRAL TO A HOSPICE IN MICHIGAN:

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5123 W. St. Joseph Hwy, Suite 204
Lansing, MI 48917
517-886-6667 - phone
800-536-6300 - toll free referral line
517-886-6737 - fax

FOR A REFERRAL IN ANOTHER STATE:

National Hospice & Palliative Care Organization
1700 Diagonal Road, Suite 300
Alexandria, VA 22314
800-658-8898 or 1-703-837-1500

TO FILE A COMPLAINT ABOUT A HOSPICE AGENCY IN MICHIGAN:

Michigan Department of Consumer
and Industry Services
Law Building, Fourth Floor
525 W. Ottawa
P.O. Box 30004
Lansing, MI 48909
800-882-6006

FOR REGULATORY INFORMATION:

Michigan Department of Consumer
and Industry Services
P.O. Box 30004
Lansing, MI 48909
517-334-8420

MEDICAID MANAGED CARE INFORMATION:

Michigan Department of Community
Health
Lewis Cass Building
320 South Walnut
Lansing, MI 48913
517-373-6440

MHPCO STATEMENT ON END OF LIFE DECISION MAKING:

The Michigan Hospice & Palliative Care Organization supports a patient's right to self-determination, to palliative care, and a patient's right to refuse unwanted intervention including the provision of artificially supplied hydration and nutrition. We believe that assisted suicide is not a component of hospice care, and further, the Michigan Hospice & Palliative Care Organization does not support the legalization of voluntary euthanasia or assisted suicide in the care of the terminally ill.

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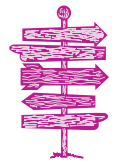
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ADDENDUM

Medical Guidelines For Determining Prognosis in Selected Non-Cancer Diseases

The National Hospice & Palliative Care Organization (NHPCO)
United Government Services, LLC (UGS)

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Introduction and Overview

This document is written to help identify which patients with non-oncologic terminal illness are likely to have a significantly decreased prognosis if the disease runs its normal course. These Guidelines may also be helpful in determining patient eligibility under the Medicare/Medicaid Hospice Benefit by defining a population that may have a life expectancy of approximately six months.

Increased access to hospice services for patients with diagnoses across the medical spectrum is also a goal of this effort. Until recently, hospice in the US has been identified with care of the end-stage cancer patient.³ Dissemination of these Guidelines to hospice programs and the medical community should facilitate hospice referrals for patients with heart, lung, liver, Alzheimer's dementia, HIV and other non-cancer diseases.

Recent studies support this effort as timely and relevant. Christakis and Escarce⁴ reported that in 1990, less than twenty percent of hospice referrals in five major states carried a non-cancer diagnosis. Since that time, the proportion of hospice admissions for diseases other than cancer has risen steadily. However, because of inherent challenges in predicting prognosis in non-cancer disease, a large proportion of patients surviving longer than six months are in this category. In the Christakis and Escarce cohort, for example, hospice patients with dementia had a median survival of 74 days, and 34.7 percent of these patients survived for longer than six months. These findings suggest that physicians and hospice programs might benefit from help in determining which non-cancer patients are likely to have a prognosis of approximately six months.

These Guidelines are a starting point, both for hospice programs evaluating patients for admission and recertification, and for critically-needed research on prognosis in end-stage disease. Pending confirmation and refinement through ongoing research with hospice patients, they provide a set of working criteria to use in determining prognosis. The

Guidelines do not pretend to predict prognosis exactly in each case. In fact, even if based directly on clinical research, any set of criteria defines a range of probabilities for mortality in a specific population. Prediction of prognosis in individual cases cannot be expected; clinical judgment is always required on the original assessment and throughout the admission.

THE MEDICAL NATURE OF THE GUIDELINES

These Guidelines are based on medical findings. However, decisions to admit patients to hospice are often not based on medical factors alone. They are routinely influenced by nonmedical factors which would generally be reflected in the treatment plan, e.g. patient decisions to receive strict symptom control rather than life-prolonging care, or selection of “optimal” rather than “maximal” treatment regimens tempered by intolerance or refusal of medication due to side-effects.

In addition, it is important to make a distinction between *admitting a patient to the hospice program* and *certifying a patient for the Medicare Hospice Benefit*. Individual hospice programs may establish admission criteria that reflect the unique characteristics and values of their communities. This may mean that some patients could be *admitted to hospice care* prior to an estimated six months before death. However, care must be taken to *certify patients for the Benefit* only when it is reasonable to conclude that their prognosis is six months or less. In other cases alternative modes of reimbursement, often provided through community support, can be sought outside the Medicare Hospice Benefit.

Emphasis should be placed on evaluating the whole person and the entirety of the illness. It is important to note, for example, that a patient may have multiple medical problems, none of which individually amount to a terminal *diagnosis*, but when taken together indicate a terminal *condition*. In short, clinical judgment that takes both medical and nonmedical factors into account is necessary for accurate estimation of prognosis.

POTENTIAL LIMITATIONS

Several caveats are in order when using these Guidelines for prognostic purposes. They are a first attempt at extrapolating a large amount of heterogeneous evidence from many studies to predict survival in non-cancer diseases (see Appendix II). Their accuracy will need to be validated by further research. These Guidelines should be applied to individual cases very cautiously, for at least the following reasons:

1. Many of the studies referenced here indicate an *increased likelihood of death*, sometimes within an uncertain time frame. The six month definition of terminal illness adopted for the Medicare Hospice Benefit has rarely been used as a specific outcome measure in most of this research. Further studies with larger populations of hospice patients are needed to determine median survival accurately with reference to the six month standard.
2. Clinical judgment must always be applied in each individual case to supplement these Guidelines. All studies are performed on large enough populations to attain statistical significance, so that individual differences in disease progression are averaged and lost to view. An individual patient who may meet Guideline criteria that were significant in a study of a large cohort might respond in unpredictable ways and have unexpected outcomes as his or her disease runs its own unique course. Therefore the Guidelines must be applied to patients not only on admission, but at intervals throughout the patient's course in hospice.
3. Many of the studies referenced here were done in institutionalized populations. They may or may not be generalizable to patients living at home with family caregivers.
4. Many studies pool patients at all stages of disease. Studies done with selected cohorts of end-stage patients might yield different conclusions. For instance, for a large population of patients with dementia at all stages of severity, antibiotics may be shown to postpone mortality.

However, the same drugs have *not* been shown to lengthen survival in the subpopulation with very end-stage dementia.⁶ Again, further research is needed in the terminal population.

5. Almost all studies have been done with patients who received standard medical therapy when they became acutely ill, thus prolonging the course of the illness. Little recent research has been done to study the natural course of untreated end-stage disease. Thus, much of the literature may be defining length of life as inappropriately *long* for patients who choose a non-curative approach.
6. The course of most non-cancer disease is inherently difficult to predict. The natural history of most non-cancer diseases is characterized by periods of relative stability punctuated by acute downturns, as opposed to the comparatively relentless, and thus more predictable, downhill course in cancer. This natural tendency toward stabilization in non-cancer disease may be augmented by hospice intervention, which may bring about a prolongation of the terminal phase due to improved patient compliance, symptom control and prevention of complications.
7. This difficulty in predicting mortality in non-cancer disease is compounded by the fact that palliation of non-cancer disease is frequently similar, and sometimes identical, to standard medical treatment. Therefore hospice can and frequently does coincidentally extend the life of the non-cancer patient in the act of palliating symptoms. This situation is new to many hospices, who have been trained to treat cancer pain but to leave treatment of cancer itself to the oncologist. To palliate cancer symptoms, hospice employs medications and other interventions which in most cases do not prolong life. Chemotherapy or radiation for palliation are generally used by hospices only when pain and symptoms can not be managed by other interventions. On the other hand, hospice frequently uses the same medications and interventions to palliate non-cancer symptoms that the primary physician or medical specialist uses for active

treatment. For instance, skillful palliation of end-stage congestive heart failure requires not only morphine for dyspnea, but also judicious use of diuretics and vasodilators. But these drugs do more than make the patient comfortable — it is well established that they also prolong life significantly.⁵ Thus good hospice care can stabilize patients with non-cancer disease, creating a dilemma for the program if the patient survives for longer than six months without evidence of serious clinical decline.

Fiscal intermediaries and hospice programs alike would benefit from a thorough awareness of these factors. These Guidelines are just a starting point in decision making in non-cancer disease. It is clear that they must be supplemented by clinical judgment at the time of admission. But frequent clinical reassessment, decisions concerning recertification versus possible discharge from the Medicare/Medicaid Hospice Benefit, thorough documentation of medical evidence of continued disease progression and cooperative review of appropriateness of care with intermediaries are all important ongoing considerations.

ACKNOWLEDGMENT

Recognition should be given to other systems of prognostication already devised for use in advanced medical illness.⁶ However, these Guidelines were developed *de novo* for several reasons. First, previous systems were developed for predicting prognosis in seriously ill hospitalized patients who were all receiving aggressive medical therapy. This is a different population than those who are generally considered hospice candidates, although this situation could change. Also, prior prognostic systems require large amounts of detailed clinical and laboratory data. This quantity and quality of information is primarily utilized in research studies, and generally unavailable to providers in the field. Additionally, unlike other systems, these Guidelines were designed for ease of application by the average hospice program, whose staff may not have access to the computer hardware, software and programming expertise needed to use

more sophisticated prognostic systems. The medical knowledge and clinical experience needed to understand and apply these Guidelines should be well within the existing capabilities of the hospice staff, ideally under the active leadership of a qualified and enthusiastic Medical Director.

Hospice Local Coverage Determination (LCD) ACTIVE Final 10-01-04 (UGS)

Indications and Limitations of Coverage and/or Medical Necessity

Medicare coverage of hospice depends on a physician's certification that an individual's prognosis is a life expectancy of six months or less if the terminal illness runs its normal course. This LCD describes guidelines to be used by Regional Home Health Intermediaries in reviewing hospice claims and by hospice providers to determine eligibility of beneficiaries for hospice benefits. Although guidelines applicable to certain disease categories are included, this LCD is applicable to all hospice patients. It is intended to be used to identify any Medicare beneficiary whose current clinical status and anticipated progression of disease is more likely than not to result in a life expectancy of six months or less.

Clinical variables with general applicability without regard to diagnosis, as well as clinical variables applicable to a limited number of specific diagnoses, are provided. Patients who meet the guidelines established herein are expected to have a life expectancy of six months or less if the terminal illness runs its normal course. Some patients may not meet these guidelines, yet still have a life expectancy of six months or less. Coverage for these patients may be approved if documentation of clinical factors supporting a less than six-month life expectancy not included in these guidelines is provided.

If a patient improves and/or stabilizes sufficiently over time while in hospice such that he/she no longer has a prognosis of six months or less from the most recent recertification evaluation or definitive interim evaluation, that patient

should be considered for discharge from the Medicare hospice benefit. Such patients can be re-enrolled for a new benefit period when a decline in their clinical status is such that their life expectancy is again six months or less. On the other hand, patients in the terminal stage of their illness who originally qualify for the Medicare hospice benefit but stabilize or improve while receiving hospice care, yet have a reasonable expectation of continued decline for a life expectancy of less than six months, remain eligible for hospice care.

A patient will be considered to have a life expectancy of six months or less if he/she meets the non-disease specific decline in clinical status guidelines described in Part I. Alternatively, the baseline non-disease specific guidelines described in Part II plus the applicable disease specific guidelines listed in the appendix will establish the necessary expectancy.

PART I. DECLINE IN CLINICAL STATUS GUIDELINES

Patients will be considered to have a life expectancy of six months or less if there is documented evidence of decline in clinical status based on the guidelines listed below. Since determination of decline presumes assessment of the patient's status over time, it is essential that both baseline and follow-up determinations be reported where appropriate. Baseline data may be established on admission to hospice or by using existing information from records. Other clinical variables not on this list may support a six-month or less life expectancy. These should be documented in the clinical record.

These changes in clinical variables apply to patients whose decline is not considered to be reversible. They are listed in order of their likelihood to predict poor survival, the most predictive first and the least predictive last. No specific number of variables must be met, but fewer of those listed first (more predictive) and more of those listed last (least predictive) would be expected to predict longevity of six months or less.

- a. Progression of disease as documented by worsening clinical status, symptoms, signs and laboratory results.**

- **Clinical Status**

- a. Recurrent or intractable infections such as pneumonia, sepsis or upper urinary tract.
- b. Progressive inanition as documented by:
 - i. Weight loss not due to reversible causes such as depression or use of diuretics
 - ii. Decreasing anthropomorphic measurements (mid–arm circumference, abdominal girth), not due to reversible causes such as depression or use of diuretics
 - iii. Decreasing serum albumin or cholesterol
- c. Dysphagia leading to recurrent aspiration and/or inadequate oral intake documented by decreasing food portion consumption.

- **Symptoms**

- a. Dyspnea with increasing respiratory rate
- b. Cough, intractable
- c. Nausea/vomiting poorly responsive to treatment
- d. Diarrhea, intractable
- e. Pain requiring increasing doses of major analgesics more than briefly.

- **Signs**

- a. Decline in systolic blood pressure to below 90 or progressive postural hypotension
- b. Ascites
- c. Venous, arterial or lymphatic obstruction due to local progression or metastatic disease
- d. Edema
- e. Pleural/pericardial effusion

- f. Weakness
- g. Change in level of consciousness
- **Laboratory (When available. Lab testing is not required to establish hospice eligibility.)**
 - a. Increasing pCO₂ or decreasing pO₂ or decreasing SaO₂
 - b. Increasing calcium, creatinine or liver function studies
 - c. Increasing tumor markers (e.g. CEA, PSA)
 - d. Progressively decreasing or increasing serum sodium or increasing serum potassium
 - i. Decline in Karnofsky Performance Status (KPS) or Palliative Performance Score (PPS) from < 70% due to progression of disease.
 - ii. Progressive decline in Functional Assessment Staging (FAST) for dementia (from =7A on the FAST)
 - iii. 5, Progression to dependence on assistance with additional activities of daily living See Part II, Section 2.
 - iv. Progressive stage 3–4 pressure ulcers in spite of optimal care.
 - v. Increasing emergency room visits, hospitalizations, or physician’s visits related to hospice primary diagnosis

**PART II. NON-DISEASE SPECIFIC BASELINE GUIDELINES
(BOTH OF THESE SHOULD BE MET)**

- a. Physiologic impairment of functional status as demonstrated by: Karnofsky Performance Status (KPS) or Palliative Performance Score (PPS) from < 70%. Note that two of the disease specific guidelines (HIV Disease, Stroke and Coma) establish a lower qualifying KPS or PPS.

- b. Dependence on assistance for two or more activities of daily living (ADLs)
 - 1. Ambulation
 - 2. Continence
 - 3. Transfer
 - 4. Dressing
 - 5. Feeding
 - 6. Bathing

See Appendix for disease specific guidelines to be used with these (Part II) baseline guidelines. The baseline guidelines do not independently qualify a patient for hospice coverage.

Note: The word “should” in the disease specific guidelines means that on medical review the guideline so identified will be given great weight in making a coverage determination. It does not mean, however, that meeting the guideline is obligatory.

PART III. CO-MORBIDITIES

Although not the primary hospice diagnosis, the presence of disease such as the following, the severity of which is likely to contribute to a life expectancy of six months or less, should be considered in determining hospice eligibility.

- a. Chronic obstructive pulmonary disease
- b. Congestive heart failure
- c. Ischemic heart disease
- d. Diabetes mellitus
- e. Neurologic disease (CVA, ALS, MS, Parkinson’s)
- f. Renal failure
- g. Liver Disease
- h. Neoplasia
- i. Acquired immune deficiency syndrome
- j. Dementia

Documentation Requirements

Documentation certifying terminal status must contain enough information to support terminal status upon review. Documentation of the applicable criteria listed under the “Indications” section of this LCD would meet this requirement. If other clinical indicators of decline not listed in this LCD form the basis for certifying terminal status, they should be documented as well. Recertification for hospice care requires the same clinical standards be met as for initial certification, but they need not be reiterated. They may be incorporated by specific reference as part (or all) of the indication for recertification.

Documentation should “paint a picture” for the reviewer to clearly see why the patient is appropriate for hospice care and the level of care provided, i.e., routine home, continuous home, inpatient respite, or general inpatient. The records should include observations and data, not merely conclusions. However, documentation expectations should comport with normal clinical documentation practices. Unless elements in the record require explanation, such as a non-morbid diagnosis or indicators of likely greater than six month survival, as stated below, no extra or additional record entries should be needed to show hospice benefit eligibility.

The amount and detail of documentation will differ in different situations. Thus a patient with metastatic small cell CA may be demonstrated to be hospice eligible with less documentation than a chronic lung disease patient. These situations are obvious. Patients with chronic lung disease, long term survival in hospice, or apparent stability can still be eligible for hospice benefits, but sufficient justification for a less than six-month prognosis should appear in the record.

If the documentation includes any findings inconsistent with or tending to disprove a less than six-month prognosis, they should be answered or refuted by other entries, or specifically addressed and explained. Most facts and observations tending to suggest a greater than six month prognosis are predictable and apparent, such as a prolonged stay in hospice

or a low immediate mortality diagnosis, as stated above. But specific entries can also call for an answer, such as an opinion by one team member or recovery of ADLs when they were part of the basis for the initial declaration of eligibility. Also the lack of certain documentation elements such as a tissue diagnosis for cancer will not create non-eligibility for the hospice benefit, but does necessitate other supportive documentation.

Documentation submitted may include information from periods of time that fall outside the billing period currently under review. Include supporting events such as a change in the level of activities of daily living, recent hospitalizations, and the known date of death (if you are billing for a period of time prior to the billing period in which death occurred.)

Documentation should support the level of care being provided to the patient during the time period under review, i.e. routine or continuous home or inpatient, respite or general. The reviewer should be able to easily identify the dates and times of changes in levels of care and the reason for the change.

FOR SHORT-TERM GENERAL INPATIENT LEVEL OF CARE, SUPPORTING DOCUMENTATION MIGHT INCLUDE:

a. Pain requiring:

1. Complicated technical delivery of medication requiring registered nurse to do calibration, tubing change, or site care
2. Frequent evaluation by physician/nurse
3. Aggressive treatment to control pain
4. Frequent medication adjustment
5. Transfusions for symptom relief

b. Symptom changes:

1. Sudden deterioration requiring intensive nursing intervention
 2. Uncontrolled nausea and vomiting
 3. Pathological fractures
 4. Respiratory distress which becomes unmanageable
 5. Open lesions needing frequent skilled care
 6. Traction and frequent repositioning requiring more than one staff member
 7. Complex wound care requiring complex dressing changes
 8. New and/or worsening delirium or agitation
- c. Psychological and social problems:**
1. Acute anxiety, fear of dying and/or depression requiring intensive interventions
 2. Collapse of family support requiring intensive skilled care in other than the home environment
- d. Patient/family teaching:**
1. Complex medications, treatments, etc.
- e. Imminent death:**
1. Requiring skilled nursing care for pain or symptom management due to a breakdown in the home support system.

REFERENCES

- 1 Jablecki CK et al, op. cit.
- 2 Adapted from Jacox A et al, *Management of Cancer Pain*. US Department of Health and Human Services, AHCPR Publication No. 94-0592, March 1994.
- 3 Callahan D. Frustrated mastery — The cultural context of death in America, in *Caring for Patients at the End of Life* [Special Issue]. *West J Med* 1995; 163:226-30.
- 4 Christakis NA et al. Survival of Medicare patients after enrollment in hospice programs. *New Eng J Med* 1996;335:172-8.
- 5 Giles TD. Optimizing the treatment of heart failure. *Curr Opin Cardiol* 1994;9 Suppl 1:S21-7.
- 6 Lynn, J et al. Accurate prognostication of death: opportunities and challenges for physicians. *West J Med* 1995;163:250-7.

APPENDIX I

a. Reasons For Denial

1. Medical review of records of hospice patients that do not document that patients meet the guidelines set forth herein may result in denial of coverage unless other clinical circumstances reasonably predictive of a life expectancy of six months or less are provided.
2. The condition of some patients receiving hospice care may stabilize or improve during or due to that care, with the expectation that the stabilization or improvement will not be brief and temporary. In such circumstances, if the patient's condition changes such that he or she no longer has a prognosis of life expectancy of six months or less, and that improvement can be expected to continue outside the hospice setting, then that patient should be discharged from hospice.

b. Coding Guidelines

1. Claims are to include an ICD-9 code for the principal diagnosis, i.e., the terminal illness. If including codes which represent comorbidities, always list these codes as secondary diagnoses.
2. NOTE: The submission of codes reflecting comorbidities on a claim does not make the hospice agency financially liable for services and medications unless they are related to the terminal diagnosis. Services not related to the terminal illness remain covered as non-hospice Part A and Part B benefits.

c. Comments:

1. This policy replaces all hospice policies for all of UGS. This policy contains significant changes from all previous hospice policies and should be considered a new policy.

2. Hospice– Determining Terminal Status – Comments: during the comment period, we received many thoughtful comments. The following is a compilation of those comments, with our responses.
 - a. A commenter requested the addition of ICD–9 codes to the section “Coding Guidelines”. We have elected to delete all the codes contained therein. The list was a group of suggested codes to be used for relevant comorbidities. The coding of secondary diagnoses is not required, and therefore the entire list is deleted.
 - b. A commenter requested the addition of the following to the guidelines for HIV, #3: “resistance to antiretrovirals”. It has been added.
 - c. A commenter requested the addition to HIV, supporting factors, “advanced liver disease”. It has been added.
 - d. A commenter noted in HIV, number 1, “loss of 33% lean body mass”, was too restrictive. We have revised this to read “loss of at least 10% lean body mass”.
 - e. A commenter suggested that in HIV, the KPS of 50% was too low, and should be changed to 70%. We feel that 50% is the more appropriate level.
 - f. A commenter noted that although the policy states that a patient with Alzheimer’s dementia should have lost the bulk of his/her verbal abilities, patients sometimes maintain such abilities well into the disease. If a patient otherwise was within the guidelines, appropriate documentation supporting his/her terminal prognosis would be given great weight in the adjudication of a claim.
 - g. We received questions about Dementia due to Alzheimer’s Disease and Related Disorders. This section is specific to Alzheimer’s dementia and closely related disorders. It may be used as a basis

for evaluating patients with other forms of dementia, if relevant. The non-disease specific section may also be used if more appropriate.

- h. Numerous comments were received regarding the section on Heart disease, both to change the wording concerning appropriate treatment of the patient's condition, and to expand the guidelines to include other forms of heart disease. We have revised the heart disease guidelines to encompass heart disease in general. The sentence concerning treatment has also been slightly revised.
- i. A commenter noted that the Heart disease section's discussion of the New York Heart Association classification was not consistent with the Association's definition of Class IV. We have revised said section to read "Symptoms ... may be present even at rest".
- j. A commenter requested the word "unexplained" be removed from Heart disease, supporting conditions, 3c. History of unexplained syncope. We have elected not to delete this word; syncope that can be explained, can probably be treated, and thus does not connote as severe a comorbidity.
- k. A commenter noted that occasionally a Liver disease patient may not have elevation of his/her INR. If the patient otherwise fulfilled the guidelines, appropriate documentation to support the patient's terminal prognosis will be given consideration.
- l. A commenter requested that we add the phrase "or is discontinuing dialysis" to number 1 of both the Acute and Chronic Renal Failure. It has been added.
- m. Comments were received urging more consideration of psychosocial issues. We understand that these issues are an integral of all

hospice care, but we also must note that psychosocial issues are not the basis of a patient's eligibility for the Medicare hospice benefit.

- n. In the section on ALS, a commenter requested that the phrase "Vital capacity less than 30% of normal" be extended to include "if available". It has been added.
- o. A commenter suggested that in Stroke and Coma, a KPS of 40% was too low; it ought to be 50%. We feel that 40% is more appropriate.
- p. A commenter suggested that the title of this document be changed to "Local Medical Review Guideline". We appreciate the concern, but "Local Medical Review Policy (LMRP)" is a CMS title; we do not feel we have the discretion to change it. We do however wish to reiterate that this policy is a group of guidelines, and that there are patients who may not strictly meet the various criteria for a particular illness, but are most certainly eligible for the Medicare hospice benefit. The most important requirement described in this LMRP is the need for appropriate documentation to support the patient's terminal prognosis.

James W. Cope, MD
Medical Director

- a. **Disease Specific Guidelines Note:** These guidelines are to be used in conjunction with the "Non-disease specific baseline guidelines" described in Part II of the basic LCD.

SECTION I

Cancer Diagnoses

- a. Disease with distant metastases at presentation OR
- b. Progression from an earlier stage of disease to metastatic disease with either
 1. A continued decline in spite of therapy
 2. Patient declines further disease directed therapy

Note: Certain cancers with poor prognoses (e.g. small cell lung cancer, brain cancer and pancreatic cancer) may be hospice eligible without fulfilling the other criteria in this section.

SECTION II

Non–Cancer Diagnoses

A. Amyotrophic Lateral Sclerosis

General Considerations:

1. ALS tends to progress in a linear fashion over time. Thus the *overall* rate of decline in each patient is fairly constant and predictable, unlike many other non–cancer diseases.
2. However, no *single* variable deteriorates at a uniform rate in all patients. Therefore, multiple clinical parameters are required to judge the progression of ALS.
3. Although ALS usually presents in a localized anatomical area, the location of initial presentation does not correlate with survival time. By the time patients become end–stage, muscle denervation has become widespread, affecting all areas of the body, and initial predominance patterns do not persist.

4. Progression of disease differs markedly from patient to patient. Some patients decline rapidly and die quickly; others progress more slowly. For this reason, the history of the rate of progression in individual patients is important to obtain to predict prognosis.
5. In end-state ALS, two factors are critical in determining prognosis: ability to breathe, and to a lesser extent ability to swallow. The former can be managed by artificial ventilation, and the latter by gastrostomy or other artificial feeding, unless the patient has recurrent aspiration pneumonia. While not necessarily a contraindication to Hospice Care, the decision to institute either artificial ventilation or artificial feeding will significantly alter six-month prognosis.
6. Examination by a neurologist within three months of assessment for hospice is advised, both to confirm the diagnosis and to assist with prognosis.

Criteria: Patients will be considered to be in the terminal stage of ALS (life expectancy of six months or less) if they meet the following criteria. (Should fulfill 1, 2, or 3).

- Patient should demonstrate critically impaired breathing capacity.
 - a. Critically impaired breathing capacity as demonstrated by all the following characteristics occurring within the 12 months preceding initial hospice certification:
 1. Vital capacity (VC) less than 30% of normal (if available);
 2. Dyspnea at rest;
 3. Patient declines mechanical ventilation;
- Patient should demonstrate both rapid progression of ALS and critical nutritional impairment.
 - a. Rapid progression of ALS as demonstrated by all the following characteristics occurring within the 12 months preceding initial hospice certification:

- b. Progression from independent ambulation to wheelchair to bedbound status;
- c. Progression from normal to barely intelligible or unintelligible speech;
- d. Progression from normal to pureed diet;
- e. Progression from independence in most or all activities of daily living (ADLs) to needing major assistance by caretaker in all ADLs.
- f. Critical nutritional impairment as demonstrated by all the following characteristics occurring within the 12 months preceding initial hospice certification:
 - g. Oral intake of nutrients and fluids insufficient to sustain life;
 - h. Continuing weight loss;
 - i. Dehydration or hypovolemia;
 - j. Absence of artificial feeding methods, sufficient to sustain life, but not for relieving hunger.
- k. Patient should demonstrate both rapid progression of ALS and life-threatening complications.
- l. Rapid progression of ALS, see 2.a above.
- m. Life-threatening complications as demonstrated by one of the following characteristics occurring within the 12 months preceding initial hospice certification:
 - 1. Recurrent aspiration pneumonia (with or without tube feedings);
 - 2. Upper urinary tract infection, e.g., pyelonephritis;
 - 3. Sepsis;
 - 4. Recurrent fever after antibiotic therapy;
 - 5. Stage 3 or 4 decubitus ulcer(s).

B. Dementia due to Alzheimer 's Disease and Related Disorders

Patients will be considered to be in the terminal stage of dementia (life expectancy of six months or less) if they meet the following criteria.

- **Patients with dementia should show *all* the following characteristics:**
 - a. Stage seven or beyond according to the Functional Assessment Staging Scale;
 - b. Unable to ambulate without assistance;
 - c. Unable to dress without assistance;
 - d. Unable to bathe without assistance;
 - e. Urinary and fecal incontinence, intermittent or constant;
 - f. No consistently meaningful verbal communication: stereotypical phrases only or the ability to speak is limited to six or fewer intelligible words.
- **Patients should have had one of the following within the past 12 months:**
 - a. Aspiration pneumonia;
 - b. Pyelonephritis or upper urinary tract infection;
 - c. Septicemia;
 - d. Decubitus ulcers, multiple, stage 3–4;
 - e. Fever, recurrent after antibiotics;
 - f. Inability to maintain sufficient fluid and calorie intake with 10% weight loss during the previous six months or serum albumin < 2.5 gm/dl.

Note: This section is specific for Alzheimer's Disease and Related Disorders, and is not appropriate for other types of dementia.

C. Heart Disease

Patients will be considered to be in the terminal stage of heart disease (life expectancy of six months or less) if they meet the following criteria. (1 and 2 should be present. Factors from 3 will add supporting documentation.)

1. At the time of initial certification or recertification for hospice, the patient is or has been already optimally treated for heart disease, or are patients who are either not candidates for surgical procedures or who decline those procedures. (Optimally treated means that patients who are not on vasodilators have a medical reason for refusing these drugs, e.g., hypotension or renal disease.)
2. Patients with congestive heart failure or angina should meet the criteria for the New York Heart Association (NYHA) Class IV. (Class IV patients with heart disease have an inability to carry on any physical activity. Symptoms of heart failure or of the anginal syndrome may be present even at rest. If any physical activity is undertaken, discomfort is increased.) Significant congestive heart failure may be documented by an ejection fraction of $\leq 20\%$, but is not required if not already available.
3. Documentation of the following factors will support but is not required to establish eligibility for hospice care:
 - a. Treatment resistant symptomatic supraventricular or ventricular arrhythmias;
 - b. History of cardiac arrest or resuscitation;
 - c. History of unexplained syncope;
 - d. Brain embolism of cardiac origin;
 - e. Concomitant HIV disease.

D. HIV Disease

Patients will be considered to be in the terminal stage of their illness (life expectancy of six months or less) if they meet the following criteria: HIV Disease (1 and 2 should be present; factors from 3 will add supporting documentation)

- CD4+ Count < 25 cells/mcl or persistent (2 or more assays at least one month apart) viral load >100,000 copies/ml, plus one of the following:
 - a. CNS lymphoma
 - b. Untreated, or persistent despite treatment, wasting (loss of at least 10% lean body mass);
 - c. Mycobacterium avium complex (MAC) bacteremia, untreated, unresponsive to treatment, or treatment refused;
 - d. Progressive multifocal leukoencephalopathy;
 - e. Systemic lymphoma, with advanced HIV disease and partial response to chemotherapy;
 - f. Visceral Kaposi's sarcoma unresponsive to therapy;
 - g. Renal failure in the absence of dialysis;
 - h. Cryptosporidium infection;
 - i. Toxoplasmosis, unresponsive to therapy.
- Decreased performance status, as measured by the Karnofsky Performance Status (KPS) scale, of =50%
- **Documentation of the following factors will support eligibility for hospice care:**
 - a. Chronic persistent diarrhea for one year; Persistent serum albumin < 2.5;
 - b. Concomitant, active substance abuse
 - c. Age >50 years;

- d. Absence of or resistance to effective antiretroviral, chemotherapeutic and prophylactic drug therapy related specifically to HIV disease;
- e. Advanced AIDS dementia complex;
- f. Toxoplasmosis;
- g. Congestive heart failure, symptomatic at rest.
- h. Advanced liver disease

E. Liver Disease

Patients will be considered to be in the terminal stage of liver disease (life expectancy of six months or less) if they meet the following criteria: (1 and 2 should be present, factors from 3 will lend supporting documentation.)

- 1. The patient should show both a and b:**
 - a. Prothrombin time prolonged more than 5 seconds over control, or International Normalized Ratio (INR) >1.5;
 - b. Serum albumin < 2.5 gm/dl.
- 2. End stage liver disease is present and the patient shows at least one of the following:**
 - a. Ascites, refractory to treatment or patient non-compliant;
 - b. Spontaneous bacterial peritonitis;
 - c. Hepatorenal syndrome (elevated creatinine and BUN with oliguria (< 400 ml/day) and urine sodium concentration < 10 mEq/l);
 - d. Hepatic encephalopathy, refractory to treatment, or patient non-compliant;
 - e. Recurrent variceal bleeding, despite intensive therapy.

3. Documentation of the following factors will support eligibility for hospice care:

- a. Progressive malnutrition;
- b. Muscle wasting with reduced strength and endurance;
- c. Continued active alcoholism (>80 gm ethanol/day);
- d. Hepatocellular carcinoma;
- e. HBsAg (Hepatitis B) positivity;
- f. Hepatitis C refractory to interferon treatment.

F. Pulmonary Disease

Patients will be considered to be in the terminal stage of pulmonary disease (life expectancy of six months or less) if they meet the following criteria. The criteria refer to patients with various forms of advanced pulmonary disease who eventually follow a final common pathway for end stage pulmonary disease. (1 and 2 should be present. Documentation of 3, 4, and 5, will lend supporting documentation.):

1. Severe chronic lung disease as documented by both a and b:
 - a. Disabling dyspnea at rest, poorly or unresponsive to bronchodilators, resulting in decreased functional capacity, e.g., bed to chair existence, fatigue, and cough: (Documentation of Forced Expiratory Volume in One Second (FEV1), after bronchodilator, less than 30% of predicted is objective evidence for disabling dyspnea, but is not necessary to obtain.)
 - b. Progression of end stage pulmonary disease, as evidenced by increasing visits to the emergency department or hospitalizations for pulmonary

infections and/or respiratory failure or increasing physician home visits prior to initial certification. (Documentation of serial decrease of FEV1>40 ml/year is objective evidence for disease progression, but is not necessary to obtain.)

2. Hypoxemia at rest on room air, as evidenced by pO₂ less than or equal to 55 mmHg; or oxygen saturation less than or equal to 88%; determined either by arterial blood gases or oxygen saturation monitors; (These values may be obtained from recent hospital records.) OR Hypercapnia, as evidenced by pCO₂ greater than or equal to 50 mmHg. (This value may be obtained from recent [within 3 months] hospital records.)
3. Right heart failure (RHF) secondary to pulmonary disease (Cor pulmonale) (e.g., not secondary to left heart disease or valvulopathy).
4. Unintentional progressive weight loss of greater than 10% of body weight over the preceding six months.
5. Resting tachycardia >100/min.

G. Renal Disease

Patients will be considered to be in the terminal stage of renal disease (life expectancy of six months or less) if they meet the following criteria:

Acute Renal Failure: (1 and either 2 or 3 should be present. Factors from 4 will lend supporting documentation.)

1. The patient is not seeking dialysis or renal transplant, or is discontinuing dialysis;
2. Creatinine clearance < 10 cc/min (<15 cc/min. for diabetics); or < 15cc/min (< 20cc/min for diabetics) with comorbidity of congestive heart failure;
3. Serum creatinine >8.0 mg/dl (>6.0 mg/dl for diabetics);

4. Comorbid conditions:

- a. Mechanical ventilation;
- b. Malignancy (other organ system);
- c. Chronic lung disease;
- d. Advanced cardiac disease;
- e. Advanced liver disease;
- f. Immunosuppression/AIDS;
- g. Albumin < 3.5 gm/dl;
- h. Platelet count < 25,000;
- i. Disseminated intravascular coagulation;
- j. Gastrointestinal bleeding.

Chronic Renal Failure: (1 and either 2 or 3 should be present. Factors from 4 will lend supporting documentation.)

- 1. The patient is not seeking dialysis or renal transplant, or is discontinuing dialysis;
- 2. Creatinine clearance <10 cc/min (< 15 cc/min for diabetics); or < 15cc/min (< 20cc/min for diabetics) with comorbidity of congestive heart failure;
- 3. Serum creatinine >8.0 mg/dl (>6.0 mg/dl for diabetics);
- 4. Signs and symptoms of renal failure:
 - a. Uremia
 - b. Oliguria (< 400 cc/24 hours);
 - c. Intractable hyperkalemia (>7.0) not responsive to treatment;
 - d. Uremic pericarditis;
 - e. Hepatorenal syndrome;
 - f. Intractable fluid overload, not responsive to treatment.

H. Stroke and Coma

Patients will be considered to be in the terminal stages of stroke or coma (life expectancy of six months or less) if they meet the following criteria:

Stroke

1. Karnofsky Performance Status (KPS) or Palliative Performance Scale (PPS) of < 40% .
2. Inability to maintain hydration and caloric intake with one of the following:
 - a. Weight loss >10% in the last 6 months or >7.5% in the last 3 months;
 - b. Serum albumin < 2.5 gm/dl;
 - c. Current history of pulmonary aspiration not responsive to speech language pathology intervention;
 - d. Sequential calorie counts documenting inadequate caloric/fluid intake.
 - e. Dysphagia severe enough to prevent patient from continuing fluids/foods necessary to sustain life and patient does not receive artificial nutrition and hydration.

Coma (any etiology):

1. **Comatose patients with any 3 of the following on day three of coma:**
 - a. abnormal brain stem response;
 - b. absent verbal response;
 - c. absent withdrawal response to pain;
 - d. serum creatinine > 1.5 mg/dl.
2. **Documentation of the following factors will support eligibility for hospice care:**

- a. Documentation of medical complications, in the context of progressive clinical decline, within the previous 12 months, which support a terminal prognosis:
 - 1. Aspiration pneumonia;
 - 2. Upper urinary tract infection (pyelonephritis);
 - 3. Refractory stage 3–4 decubitus ulcers;
 - 4. Fever recurrent after antibiotics.
- b. Documentation of diagnostic imaging factors which support poor prognosis after stroke include:
 - 1. For non-traumatic hemorrhagic stroke:**
 - 1. Large-volume hemorrhage on CT:
 - a. Infratentorial: =20 ml.;
 - b. Supratentorial: =50 ml.
 - 2. Ventricular extension of hemorrhage;
 - 3. Surface area of involvement of hemorrhage =30% of cerebrum;
 - 4. Midline shift =1.5 cm.;
 - 5. Obstructive hydrocephalus in patient who declines, or is not a candidate for, ventriculoperitoneal shunt.
 - 2. For thrombotic/embolic stroke:**
 - 1. Large anterior infarcts with both cortical and subcortical involvement;
 - 2. Large bihemispheric infarcts;
 - 3. Basilar artery occlusion;
 - 4. Bilateral vertebral artery occlusion.

APPENDIX II

Medical Guidelines for Determination of Prognosis: Type, Strength and Consistency of Evidence

These guidelines were constructed whenever possible on the basis of evidence from the medical literature concerning early mortality in non-cancer diseases. This evidence may be grouped in the following categories:²

- I. Meta-analysis of multiple, well-designed controlled studies.
- II. At least one well-designed experimental study.
- III. Well-designed, quasi-experimental studies:
 - A. Nonrandomized controlled.
 - B. Single group pre/post.
 - C. Cohort.
 - D. Time Series.
 - E. Matched case-controlled.
- IV. Well-designed non-experimental studies.
 - A. Comparative and correlational descriptive and case studies.
- V. Case reports and clinical examples.

Strength and consistency of evidence may then be sorted as follows:

- A. There is evidence of Type I or consistent findings from multiple studies of Types II, III or IV.

- B. There is evidence of Types II, III or IV, and findings are generally consistent.
- C. There is evidence of Types II, III or IV, but findings are inconsistent.
- D. There is little or no evidence, or there is Type V evidence only.

There has been no attempt in these Guidelines to classify each recommendation individually. In general, most of these Guidelines would be classified as within Group B, with a number in Groups A and C. With further more targeted research on mortality in end-stage non-cancer disease, it would be expected that Guidelines would evolve upward in this classification to Categories A or B.

APPENDIX III

Karnofsky Performance Status Scale Definitions Rating (%) Criteria

| | | |
|---|-----|---|
| Able to carry on normal activity and to work; no special care needed. | 100 | Normal no complaints; no evidence of disease. |
| | 90 | Able to carry on normal activity; minor signs or symptoms of disease. |
| | 80 | Normal activity with effort; some signs or symptoms of disease. |
| Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed. | 70 | Cares for self; unable to carry on normal activity or to do active work. |
| | 60 | Requires occasional assistance, but is able to care for most of his needs. |
| | 50 | Requires considerable assistance and frequent medical care. |
| Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly. | 40 | Disabled; requires special care and assistance. |
| | 30 | Severely disabled; hospital admission is indicated although death not imminent. |
| | 20 | Very sick; hospital admission necessary; active supportive treatment necessary. |
| | 10 | Moribund; fatal processes progressing rapidly. |
| | 0 | Dead |

Oxford Textbook of Palliative Medicine, Oxford University Press. 1993;109.

APPENDIX IV

New York Heart Association (NYHA) Functional Classification

- Class I.** Patients with cardiac disease, but without resulting limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnea, or anginal pain.
- Class II.** Patients with cardiac disease resulting in slight limitation of physical activity. They are comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnea, or anginal pain.
- Class III.** Patients with marked limitation of physical activity. They are comfortable at rest. Less than ordinary activity causes fatigue, palpitation, dyspnea, or anginal pain.
- Class IV.** Patients with cardiac disease resulting in inability to carry on any physical activity without discomfort. Symptoms of heart failure or of the anginal syndrome may be present even at rest. If any physical activity is undertaken, discomfort is increased.

APPENDIX V

Functional Assessment Staging (FAST)

(Check highest consecutive level of disability.)

- 1. No difficulty either subjectively or objectively.
- 2. Complains of forgetting location of objects. Subjective work difficulties.
- 3. Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity.*
- 4. Decreased ability to perform complex tasks, e.g., planning dinner for guests, handling personal finances (such as forgetting to pay bills), difficulty marketing, etc.
- 5. Requires assistance in choosing proper clothing to wear for the day, season or occasion, e.g., patient may wear the same clothing repeatedly, unless supervised.*
- 6. A) Improperly putting on clothes without assistance or cuing (e.g., may put street clothes on over night clothes, or put shoes on wrong feet, or have difficulty buttoning clothing) occasionally or more frequently over the past weeks.*
- B) Unable to bathe properly (e.g., difficulty adjusting bath-water temperature) occasionally or more frequently over the past weeks.*
- C) Inability to handle mechanics of toileting (e.g., forgets to flush the toilet, does not wipe properly or properly dispose of toilet tissue) occasionally or more frequently over the past weeks.*

- D) Urinary incontinence (occasionally or more frequently over the past weeks).*
- E) Fecal incontinence (occasionally or more frequently over the past weeks).*
- 7. A) Ability to speak limited to approximately a half a dozen intelligible different words or fewer, in the course of an average day or in the course of an intensive interview.
- B) Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview (the person may repeat the word over and over).
- C) Ambulatory ability is lost (cannot walk without personal assistance).
- D) Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests (arms) on the chair).
- E) Loss of ability to smile.
- F) Loss of ability to hold up head independently.

* Scored primarily on the basis of information obtained from a knowledgeable informant and/or category.

Reisberg, B. Functional assessment staging (FAST). *Psychopharmacology Bulletin*, 1988; 24:653-659.

APPENDIX VI

Typical Time Course of Alzheimer's Disease (AD)

Hospice Parameters:
"Minimum Magnitude
of Severity"

| Clinical Diagnosis | Incipient or Question AD | Mild AD | Moderate AD | Moderate-Severe AD | Serve AD |
|--------------------|--------------------------|---------|-------------|--------------------|------------------------|
| FAST Stage | 3 | 4 | 5 | 6 | 7 |
| FAST Substage | | | | a b c d e | a b c d e f |
| Years: | 0 | 7 | 9 | 10.5 | 13 |
| Mini Mental | 29 | 25 | 19 | 14 | 5 |
| | 25 | 19 | 14 | 5 | 0 Usual Point of Death |

Reisberg, et al., Alzheimer's Disease and Associated Disorders, 1994; 8 (Suppl.) S 188-S 205.

APPENDIX VII

Diagnostic Imaging Factors Indicating Poor Prognosis After Stroke

- A. For non-traumatic hemorrhagic stroke:
 - 1. Large-volume hemorrhage on CT:
 - a. Infratentorial: ≥ 20 ml.¹
 - b. Supratentorial: ≥ 50 ml.¹
 - 2. Ventricular extension of hemorrhage.¹
 - 3. Surface area of involvement of hemorrhage $\geq 30\%$ of cerebrum.¹
 - 4. Midline shift ≥ 1.5 cm.¹
 - 5. Obstructive hydrocephalus in patient who declines, or is not a candidate for, ventriculoperitoneal shunt.¹
- B. For thrombotic/embolic stroke:
 - 1. Large anterior infarcts with both cortical and subcortical involvement.¹
 - 2. Large bihemispheric infarcts.¹
 - 3. Basilar artery occlusion.¹
 - 4. Bilateral vertebral artery occlusion.¹

Sources of Information and Basis for Decision

- ICD-9-CM 2003, ©2002 Practice Management Information Corporation.
- Medicare Contractor Medicare Directors Hospice Workgroup.
- All previously published UGS Local Medical Review Policies
- B. Friedman, M. Harwood, M. Shields. Barriers and Enablers to Hospice Referrals: An Expert Overview. *J Palliative Medicine* 2002; 5; 73-84.
- K. Ogle, B. Mavis, G. Wyatt. Physicians and Hospice Care: Attitudes, Knowledge, and Referrals. *J Palliative Medicine* 2002; 5; 85-92.
- K. Ogle, B. Mavis, T. Wang. Hospice and Primary Care Physicians: Attitudes, Knowledge, and Barriers. *A J Hospice & Palliative Care* 2003; 20; 41-51.
- N. Christakis, E. Lamont. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. *British Medical Journal* 2000; 320; 469-472.
- E. Lamont, N. Christakis. Prognostic Disclosure to Patients with Cancer near the End of Life. *Annals of Internal Medicine* 2001; 134;1097-1143.
- Other Medicare contractors, specialty societies, and specialty consultants.

**NARRATIVE SUMMARY
OF PROGNOSIS DOCUMENTATION**

Documentation should be complete, consistent, concise, specific, measurable, and descriptive.

Diagnosis: Present underlying illness(es) and all other illness(es) affecting the terminal diagnosis:

Co-morbidity that affects the prognosis: _____

History and progression of the illness(es): _____

Physical baseline (e.g., weight and weight change, vital signs, heart rhythms, rales, degree of edema):

Laboratory (if pertinent): _____

Physician's prognosis stating why there is a life expectancy of 6 months or less (e.g., Patient depressed, will not eat and does not want anything done, or has had optimal therapy for illness.):

RN Signature

Date

Physician signature

Complete this form and attach it to the appropriate disease specific worksheet

**WORKSHEET
FOR DETERMINING PROGNOSIS**

Dementia

The purpose of this worksheet is to guide initial and recertification assessments. It must be accompanied by narrative documentation. These are guidelines only: clinical judgement is required in each case. Construct a narrative from the information on this worksheet and information from the patient's physician and record on back. The patient should be re-evaluated at specific intervals set by the interdisciplinary team and within 60 days of clinical stabilization. This form may be used for initial and subsequent re-evaluation.

Pt. Name: _____ ID#: _____ Date: _____

Both 1 and 2 must be present as evidence of hospice appropriateness.

1. Is patient severely demented? Yes No

Patient should be at or beyond Stage 7 of the Functional Assessment Staging Scale. *Check level:*

- ___ 7A Ability to speak is limited to approximately 6 intelligible words or fewer, in the course of an average day or in the course of an intensive interview.
___ 7B Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview (the person may repeat the word over and over).
___ 7C Ambulatory ability is lost (cannot walk without personal assistance).
___ 7D Cannot sit up without assistance (e.g., patient will fall over if there are not lateral rests (arms) on the chair).
___ 7E Loss of ability to smile.
___ 7F Loss of ability to hold up head independently.

Patient should show **all** of the following characteristics. *Check all that apply:*

- ___ inability to ambulate independently (cannot walk without personal assistance)
___ unable to dress without assistance
___ unable to bathe properly
___ incontinence of urine *and* stool (occasionally or more frequently, over the past weeks as reported by a knowledgeable informant or caregiver)
___ unable to speak or communicate meaningfully (*see 7A above*)

2. Has the patient had one or more of the following medical complications related to dementia during the past year? Yes No

(conditions should have been severe enough for hospitalization whether or not hospitalization occurred).

Check all that are appropriate:

- ___ aspiration pneumonia
___ upper urinary tract infection
___ septicemia
___ decubitus ulcers, multiple, stage 3-4
___ fever recurrent after antibiotics
___ inability or unwillingness to take food or fluids sufficient to sustain life; not a candidate for feeding tube or parenteral nutrition

Patients who are receiving tube feedings must have documented impaired nutritional status as indicated by either:

- ___ unintentional, progressive weight loss of greater than 10% over prior 6 months, or
___ serum albumin less than 2.5 gm/dl (may be helpful prognostic indicator but should not be used by itself)

Attach completed "Narrative Summary of Prognosis Documentation" form to this form

**WORKSHEET
FOR DETERMINING PROGNOSIS**

General Guidelines - All Diagnoses

The purpose of this worksheet is to guide initial and recertification assessments. It must be accompanied by narrative documentation. These are guidelines only: clinical judgment is required in each case. Construct a narrative from the information on this worksheet and information from the patient's physician and record on back. The patient should be re-evaluated at specific intervals set by the interdisciplinary team and within 60 days of clinical stabilization. This form may be used for initial and subsequent re-evaluation.

Pt. Name: _____ ID#: _____ Date: _____

The patient should meet the following criteria:

1. Life limiting condition Yes No
2. Pt/family informed condition is life limiting Yes No
3. Pt/family elected palliative care Yes No
4. Documentation of clinical progression of disease Yes No

Evidenced by (*check all that apply and secure copies of documentation for hospice record*):

- ____ serial physician assessment
- ____ laboratory studies
- ____ radiologic or other studies
- ____ multiple Emergency Dept. visits
- ____ inpatient hospitalizations
- ____ home health nursing assessment if patient homebound

and/or

5. Recent decline in functional status Yes No

Evidenced by either:

- A. Karnofsky Performance Status \leq 50% Yes No

Check level:

- ____ 50% Requires considerable assistance and frequent medical care
- ____ 40% Disabled; requires special care and assistance
Unable to care for self; disease may be progressing rapidly
- ____ 30% Severely disabled; although death is not imminent
- ____ 20% Very sick; active supportive treatment necessary
- ____ 10% Moribund; fatal processes progressing rapidly

and/or

- B. Dependence in 3 of 6 Activities of Daily Living Yes No

Check activities in which patient is dependent:

- ____ bathing
- ____ dressing
- ____ feeding
- ____ transfers
- ____ continence of urine and stool
- ____ ambulation to bathroom

and/or

6. Recent impaired nutritional status Yes No

Evidenced by (*check all appropriate*):

- ____ unintentional, progressive weight loss of 10% over past six months
- ____ serum albumin less than 2.5 gm/dl (may be helpful prognostic indicator but should not be used by itself)

Attach completed "Narrative Summary of Prognosis Documentation" form to this form

**WORKSHEET
FOR DETERMINING PROGNOSIS**

Pulmonary Disease

The purpose of this worksheet is to guide initial and recertification assessments. It must be accompanied by narrative documentation. These are guidelines only: clinical judgement is required in each case. Construct a narrative from the information on this worksheet and information from the patient's physician and record on back. The patient should be re-evaluated at specific intervals set by the interdisciplinary team and within 60 days of clinical stabilization. This form may be used for initial and subsequent re-evaluations.

Pt. Name: _____ ID#: _____ Date: _____

Patient has severe lung disease Yes No
Evidenced by (check all that apply):

| Symptoms | Signs |
|--|---|
| <input type="checkbox"/> dyspnea at rest <input type="checkbox"/> dyspnea on exertion <input type="checkbox"/> housebound, chairbound <input type="checkbox"/> oxygen-dependent <input type="checkbox"/> copious/purulent sputum <input type="checkbox"/> recurrent infections <input type="checkbox"/> severe cough | <input type="checkbox"/> cyanosis: blue lips, fingertips <input type="checkbox"/> pulmonary hyperinflation: barrel-chested <input type="checkbox"/> pursed-lip breathing <input type="checkbox"/> accessory muscles of respiration <input type="checkbox"/> retractions: supraclavicular <input type="checkbox"/> increased expiratory phase: slowed forced expiration <input type="checkbox"/> wheezing <input type="checkbox"/> diminished breath sounds <input type="checkbox"/> depressed diaphragm |

- ___ poor response to bronchodilators
- ___ forced expiratory volume in one second (FEV1) after bronchodilator, less than 30% of predicted*
- ___ increased visits to Emergency Department
- ___ increased hospitalizations for pulmonary infections/respiratory failure
- ___ decrease in FEV1 on serial testing of greater than 40 ml per year*
- ___ presence of cor pulmonale or right heart failure due to lung disease evidenced by:
 - ___ echocardiographic documentation*
 - ___ EKG*
 - ___ chest x-ray*
 - ___ physical signs of RHF
- ___ hypoxemic at rest on supplemental oxygen
 - ___ pO₂ , < 55 mm Hg on supplemental O₂
 - ___ O₂ saturation < 88% on supplemental O₂
- ___ hypercapnia (pCO₂ ≥ 50 mm Hg)
- ___ unintentional weight loss > 10% of body weight in past six months
- ___ resting tachycardia (heart rate > 100 per minute)

* These tests are helpful evidence but should not be required if not readily available.

Attach completed "Narrative Summary of Prognosis Documentation" form to this form

**WORKSHEET
FOR DETERMINING PROGNOSIS**

HIV Disease

The purpose of this worksheet is to guide initial and recertification assessments. It must be accompanied by narrative documentation. These are guidelines only; clinical judgement is required in each case. Construct a narrative from the information on this worksheet and information from the patient's physician and record on back. The patient should be re-evaluated at specific intervals set by the interdisciplinary team and within 60 days of clinical stabilization. This form may be used for initial and subsequent re-evaluation.

Pt. Name: _____ ID#: _____ Date: _____

The following factors combined with clinical judgment, may help decide whether individual patients are hospice appropriate:

1. CD4+ count
 - ___ > 50 cells/mc/L: Patient probably has a prognosis of > 6 months unless there is a non-HIV-related co-existing life-threatening disease
 - ___ < 25 cells/mc/L:
 - ___ measured during a period when patient is relatively free of acute illness
 - ___ observed disease progression and decline in functional status

2. Viral load
 - ___ > 100,000 copies/ml: Patient may have a prognosis of less than 6 months
 - ___ < 100,000 copies/ml and meet the following criteria:
 - ___ patient has elected to forego antiretroviral and prophylactic medication
 - ___ functional status is declining
 - ___ experiencing complications (see 4 below)

3. Life-threatening complications with median survival (check all that are present):

| COMPLICATION | USUAL LIFE EXPECTANCY |
|---|------------------------|
| ___ CNS lymphoma | 2.5 months |
| ___ Progressive multifocal leukoencephalopathy | 4 months |
| ___ Cryptosporidiosis | 5 months |
| ___ Wasting (loss of 33% lean body mass) | < 6 months |
| ___ MAC bacteremia, untreated | < 6 months |
| ___ Visceral Kaposi's sarcoma unresponsive to therapy | 6 months mortality 50% |
| ___ Renal failure, refuses or fails dialysis | < 6 months |
| ___ AIDS dementia complex | 6 months |
| ___ Toxoplasmosis | 6 months |

4. The following factors have been shown to decrease survival significantly and should be documented if present:
 - ___ chronic persistent diarrhea for one year, regardless of etiology
 - ___ persistent serum albumin < 2.5 gm/dl
 - ___ concomitant substance abuse
 - ___ age greater than 50
 - ___ decisions to forego antiretroviral, chemotherapeutic, and prophylactic drug therapy related specifically to HIV disease
 - ___ congestive heart failure, symptomatic at rest

Attach completed "Narrative Summary of Prognosis Documentation" form to this form

WORKSHEET FOR DETERMINING PROGNOSIS

Liver Disease

The purpose of this worksheet is to guide initial and recertification assessments. It must be accompanied by narrative documentation. These are guidelines only: clinical judgement is required in each case. Construct a narrative from the information on this worksheet and information from the patient's physician and record on back. The patient should be re-evaluated at specific intervals set by the interdisciplinary team and within 60 days of clinical stabilization. This form may be used for initial and subsequent re-evaluation.

Pt. Name: _____ ID#: _____ Date: _____

The following factors have been shown to correlate with poor short-term survival in advanced cirrhosis of the liver due to alcoholism, hepatitis, or uncertain causes (cryptogenic). Their effects are additive, i.e., prognosis worsens with the additional of each one and clinical judgement is vital. The following factors should be followed and reviewed over time.

1. Patient is not a candidate for liver transplantation
2. Laboratory indicators of severely impaired liver function should show **both** of the following:
 - Prothrombin time prolonged more than 5 sec. over control
 - Serum albumin < 2.5 gm/dl
3. Clinical indicators of end-stage liver disease (patient should show at least one of the following):
 - Ascites
 - refractory to sodium restriction and diuretics: spironolactone 75-150 mg/day plus furosemide > 40 mg/day
 - patient non-compliant
 - Spontaneous bacterial peritonitis (median survival 30% at one year; high mortality even when infection cured initially if liver disease is severe or accompanied by renal disease.)
 - Hepatorenal syndrome (usually occurs during hospitalization; survival generally days to weeks)
 - patient has cirrhosis and ascites
 - elevated creatinine and BUN
 - oliguria 400 ml/day
 - urine sodium concentration < 10 mEq/l
 - Hepatic encephalopathy,
 - refractory to protein restriction and lactulose or neomycin
 - patient non-compliant

| Symptoms | Signs |
|---|---|
| <input type="checkbox"/> decreased awareness of environment <input type="checkbox"/> sleep disturbance <input type="checkbox"/> depression <input type="checkbox"/> emotional lability <input type="checkbox"/> somnolence <input type="checkbox"/> slurred speech <input type="checkbox"/> obtundation | <input type="checkbox"/> flapping tremor of asterixis (in earlier stages) <input type="checkbox"/> stupor (late-stage) <input type="checkbox"/> coma (late-stage) |

- Recurrent variceal bleeding: patient should have re-bled despite therapy which currently includes:
 - injection sclerotherapy or band ligation, if available
 - oral beta blockers
 - transjugular intrahepatic portosystemic shunt (TIPS)
 - patient refused further therapy
- 4. The following factors have been shown to worsen prognosis and should be documented if present:
 - progressive malnutrition
 - muscle wasting with reduced strength and endurance
 - continued active alcoholism (> 80 g ethanol per day)
 - hepatocellular carcinoma
 - HBsAg positivity

Attach completed "Narrative Summary of Prognosis Documentation" form to this form

**WORKSHEET
FOR DETERMINING PROGNOSIS**

Renal Disease

The purpose of this worksheet is to guide initial and recertification assessments. It must be accompanied by narrative documentation. These are guidelines only: clinical judgement is required in each case. Construct a narrative from the information on this worksheet and information from the patient's physician and record on back. The patient should be re-evaluated at specific intervals set by the interdisciplinary team and within 60 days of clinical stabilization. This form may be used for initial and subsequent re-evaluation.

Pt. Name: _____ ID#: _____ Date: _____

Absent other comorbid conditions, the patient should not be seeking dialysis or renal transplant. Patients who do refuse dialysis or transplant are generally appropriate for hospice services if they fit dialysis criteria.

1. Laboratory criteria for renal failure (both must be present)
- creatine clearance of < 10cc/min (<15cc/min for diabetics), and
 - serum creatinine > 8.0 mg/dl (>6.0 mg/dl for diabetics)

NOTE: Creatinine clearance may be estimated by using the following formula:

$$C_{\text{creat}} = \frac{(140 - \text{age in yrs.}) (\text{body wt. in kg})}{72} \text{ multiply by 0.85 for women}$$

(72) (serum creat in mg/dl)

2. Clinical signs and syndromes associated with renal failure (*check all which are present*):
- uremia: clinical signs of renal failure:
 - confusion, obtundation
 - intractable nausea and vomiting
 - generalized pruritis
 - restlessness, "restless legs"
 - oliguria: urine output < 400 cc/24 hrs.
 - intractable hyperkalemia: persistent serum potassium > 7.0 not responsive to medical management
 - uremic pericarditis
 - hepatorenal syndrome
 - intractable fluid overload
3. In hospitalized patients with ARF, these comorbid conditions predict early mortality (*check all that apply for this patient*):
- mechanical ventilation
 - malignancy -- other organ systems
 - chronic lung disease
 - advanced cardiac disease
 - advanced liver disease
 - sepsis
 - immunosuppression/AIDS
 - albumen < 3.5 gm/dl
 - cachexia
 - platelet count < 25,000
 - age > 75
 - disseminated intravascular coagulation
 - gastrointestinal bleeding

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WORKSHEET FOR DETERMINING PROGNOSIS

Stroke and Coma

The purpose of this worksheet is to guide initial and recertification assessments. It must be accompanied by narrative documentation. These are guidelines only: clinical judgement is required in each case. Construct a narrative from the information on this worksheet and information from the patient's physician and record on back. The patient should be re-evaluated at specific intervals set by the interdisciplinary team and within 60 days of clinical stabilization. This form may be used for initial and subsequent re-evaluation.

Pt. Name: _____ ID#: _____ Date: _____

After stroke, patients who do not die during the acute hospitalization tend to stabilize with supportive care only. Continuous decline in clinical or functional status over time means that the patient's prognosis is poor.

- Acute phase patients.** Immediately following a hemorrhagic or ischemic stroke, any of the following are strong indicators of early mortality:
 - ___ Coma or persistent vegetative state secondary to stroke, beyond three days' duration
 - ___ In post-anoxic stroke, coma or severe obtundation, accompanied by severe myoclonus, persistent beyond 3 days past the anoxic event
 - ___ Comatose patients with any 4 of the following on day 3 of coma had 97% mortality by two months:
 - ___ abnormal brain stem response
 - ___ absent verbal response
 - ___ absent withdrawal response to pain
 - ___ serum creatinine >1.5mg/dl
 - ___ age > 70
 - ___ Dysphagia severe enough to prevent the patient from receiving food and fluids necessary to sustain life, in a patient who declines or is not a candidate for artificial nutrition and hydration
 - ___ If available, CT or MRI scans may indicate decreased likelihood of survival (see Appendix V for list)
- Chronic phase patients.** The following clinical factors may correlate with poor survival and should be documented.
 - ___ Age > 70
 - ___ Poor functional status as evidenced by Karnofsky score of < 50%
 - ___ 50% Requires considerable assistance and frequent medical care
 - ___ 40% Disabled; requires special care and assistance; unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly
 - ___ 30% Severely disabled; hospital admission is indicated although death is not imminent
 - ___ 20% Very sick; hospital admission necessary; active supportive treatment necessary
 - ___ 10% Moribund; fatal processes progressing rapidly
 - ___ Post stroke dementia as evidenced by a FAST score greater than 7
 - ___ 7A Ability to speak is limited to approximately 6 intelligible words or fewer, in the course of an average day or in the course of an intensive interview
 - ___ 7B Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview (the person may repeat the word over and over)
 - ___ 7C Ambulatory ability is lost (cannot walk without personal assistance)
 - ___ 7D Cannot sit up without assistance (e.g., patient will fall over if there are not lateral rests (arms on the chair)
 - ___ 7E Loss of ability to smile
 - ___ 7F Loss of ability to hold up head independently
 - ___ Poor nutritional status, whether on artificial nutrition or not:
 - ___ unintentional progressive weight loss of greater than 10% over prior six months
 - ___ serum albumin less than 2.5 gm/dl (may be helpful prognostic indicator but should not be used by itself)
 - ___ Medical complications related to debility and progress clinical decline
 - ___ aspiration pneumonia
 - ___ upper urinary tract infection (pyelonephritis)
 - ___ sepsis
 - ___ refractory stage 3-4 decubitus ulcers
 - ___ fever recurrent after antibiotics

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**WORKSHEET
FOR DETERMINING PROGNOSIS**

Amyotrophic Lateral Sclerosis (ALS)

The purpose of this worksheet is to guide initial and recertification assessments. It must be accompanied by narrative documentation. These are guidelines only; clinical judgement is required in each case. Construct a narrative from the information on this worksheet and information from the patient's physician and record on back. The patient should be re-evaluated at specific intervals set by the interdisciplinary team and within 60 days of clinical stabilization. This form may be used for initial and subsequent re-evaluation.

Pt. Name: _____ ID#: _____ Date: _____

In determining prognosis for the ALS patient, examination by a neurologist within three months of assessment is advised. All patients must meet criteria #1-rapid progression of ALS as well as either 2A-critically impaired ventilatory capacity, 2B-critical nutritional impairment, or 2C-life-threatening complications.

1. **Rapid progression of ALS.** Most of disability should have developed in past 12 months. *Check examples which apply:*
 - ___ progression from independent ambulation to wheelchair or bed-bound
 - ___ progression from normal to barely intelligible or unintelligible speech
 - ___ progression from normal to blenderized diet
 - ___ progression from independence in all or most ADLs to requiring assistance in all ADLs

Patients with slow progression may survive for longer periods, although clinical judgment may still indicate they may be within six months of death.

2. **At least one of the following must also apply:**
 - A. Critically impaired ventilatory capacity
 - ___ vital capacity (VC) less than 30% of predicted
 - ___ significant dyspnea at rest
 - ___ supplemental oxygen required at rest
 - ___ intubation or tracheostomy and mechanical ventilation considered (Note: patients receiving ventilation assistance may survive longer than six months unless there is a life-threatening comorbid condition.)

 - B. Critical nutritional impairment
 - ___ artificial feeding not elected or discontinued
 - ___ oral intake insufficient
 - ___ continued weight loss
 - ___ dehydration or hypovolemia

 - C. Life-threatening complications
 - ___ recurrent aspiration pneumonia
 - ___ decubitus ulcers, multiple, stage 3-4, particularly if infected
 - ___ upper urinary tract infection, e.g. pyelonephritis
 - ___ sepsis
 - ___ fever recurrent after antibiotics

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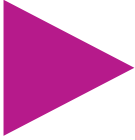
The Maggie Allesee Center for Quality of Life (MACQL), with the mission “to empower people on life’s journey,” is located at Hospice of Michigan’s corporate headquarters in the historic Brush Park neighborhood in downtown Detroit. The MACQL was started with a generous \$3 million endowment from Detroit-area

philanthropist Maggie Allesee, and is a hub for research, education, innovation and community partnerships. John Finn, M.D., noted speaker and author in hospice/palliative medicine, is the MACQL’s medical director. The aim of the Maggie Allesee Center for Quality of Life is to enhance hospice and palliative practice, and its work distinguishes Hospice of Michigan as one of the leading hospice care providers in the nation.

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