HARBOR
HOSPICE
& PALLIATIVE CARE

Resource Book

- **Palliative Care Information**
- **Hospice Eligibility Guidelines**
- **Supportive Resources**

Dear Colleagues,

This tool provides an overview of palliative care referrals and helps identify patients who may be appropriate for hospice care. It is not intended to supersede your clinical judgment regarding a patient's prognosis.

Per CMS regulatory interpretation, Debility and Adult Failure to Thrive can no longer be used as primary hospice diagnoses. However, they may still be listed as secondary conditions in support of the primary diagnosis.

Please utilize the prognostication tools in the resources section—I have found them to be particularly helpful in assessing patients with uncertain prognoses.

Additionally, we have included a section on the Harbor Palliative Care program.

Our medical team is available to assist you and welcomes any questions. Please feel free to call 231.728.3442 if you would like to discuss any concerns.

Regards,
Dr. Caitlin Fulton, D.O.
Medical Director, Harbor Hospice and Harbor Palliative Care

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Harbor Palliative Care

Palliative care is an intentional, supportive, and comprehensive approach proven to improve the quality of life for patients with serious illnesses. It focuses on managing and relieving suffering—whether physical, psychosocial, or spiritual—through early identification, thorough evaluation, and targeted treatment of pain and other symptoms. Palliative care is a form of supportive care that can be provided alongside other medical treatments.

When caring for a patient with a serious illness, consider a palliative care referral or consultation in the following situations:

A. Patient:

- Needs help with complex decision-making and assistance with goals or a plan of care
- Is experiencing unacceptable levels of pain or other distressing symptoms
- Has had multiple hospital admissions for the same diagnosis within the last three months
- Has had a prolonged hospital stay (>5 days) without improvement
- Has had a prolonged ICU stay without improvement
- Is in an ICU setting with a poor prognosis or has been recently discharged from the ICU

- Needs assistance in determining hospice eligibility
- Has opted out of hospice care

B. Uncontrolled Physical Symptoms:

- Pain
- Dyspnea
- Nausea/vomiting
- Cough
- Constipation
- Delirium
- Agitation
- Depression/anxiety
- Insomnia
- Lack of appetite
- Declining performance status

C. Advanced Conditions Leading to Serious Illness:

- Cancer
- COPD
- Acute stroke with coma
- End-stage renal disease
- CHF
- Chronic disease that is life-limiting
- Liver disease
- Other conditions complicating care

D. Progressive Conditions:

- ALS, MS, Dementia, Parkinson's
- Prior stroke with progressive sequelae (consider feeding tube or tracheostomy)

Palliative Care Can be Provided in a Variety of Settings:

The Harbor Palliative Care team visits patients in nursing homes, assisted living centers, and private homes. Oncology patients are seen at the Cancer & Hematology Centers of Western Michigan.

Initiating a Palliative Care Consult Referral:

Anyone can request a palliative care consult, but a physician's order from the patient's actively involved physician is required. Key concepts to remember when making a referral:

- Palliative care is not hospice care, nor is it end-of-life care.
- Palliative care **is appropriate at any age and at any stage of a serious illness and can be provided alongside curative treatment.**
- Medical studies have shown that palliative care **improves the quality of life for both the patient and their family.**
- Palliative care is **not** a pain clinic. We do not treat chronic pain or substance use disorders.

Harbor Hospice

The statement we read most frequently in our Family Evaluation of Hospice Services is, **"We wish we would have called you sooner."**

This sentiment can be attributed to several reasons:

- Families have more quality time to spend with their loved ones.
- A 24/7 support system is in place, providing families with a greater sense of relief, thus reducing anxiety.
- Patients are often able to confide in and resolve intensely personal issues with end-of-life professionals, helping to relieve stress and guilt.
- Pain is managed, and stress is reduced. A care "Plan for Living" is created with the patient's input. The focus is on living out their journey on their terms with the help of our expertise.
- Harbor Hospice provides care to all patients, regardless of their ability to pay.
- We provide services in Muskegon, Oceana, Ottawa, Mason, and Newaygo Counties.
- Grief support services are provided to the family for 13 months following the loss of a loved one.

Who Can Receive Hospice Care?

A patient is eligible for hospice care if a physician determines that the patient has **six months or less to live** if the terminal illness runs its normal course. Patients must be re-assessed for eligibility at regular intervals as determined by CMS; however, there is no limit on the amount of time a patient can spend under hospice care, as long as the patient continues to meet the criteria.

The following pages offer eligibility guidelines for coverage under hospice care. Should you have any questions, please don't hesitate to call 231.728.3442. We are happy to consult with you, or if you prefer, someone from our intake department will call your patient and get back to you regarding their determination.

Have You Ever Asked Yourself the Following Question?

During a visit with your patient, have you ever thought, "Would I be surprised if this patient were to pass away in the next 6-12 months?" If so, there is a lot that can be done to support you, your patient, and their family. Consider Harbor Hospice as a resource for advance care planning (ACP), palliative care, and hospice care. The sooner you talk with families about these services, the more time they have to make the most of their time together.

Adult Failure to Thrive

***Only use as a secondary diagnosis** **There must be an alternate primary diagnosis.*

Usually, two of the following must be present:

- 10% weight loss in 6 months
- BMI ≤ 22 (usually present for this diagnosis to be used)
- Functional dependence/total care
- Frequent ER/hospital/office visits
- Pressure ulcer Stage 3-4
- PPS ≤ 50% (see pages 10-11)
- Albumin < 2.5 g/dL

ALS

Rapidly progressive symptoms within 12 months, including:

- Loss of ambulation
- Loss of speech
- Diet change
- Diminished respiratory function or nutritional impairment
- Life-threatening infectious complications (respiratory, urinary, sepsis, fever)

→ Also, the patient is not pursuing life-prolonging measures.

→ May still qualify with tube feeding or noninvasive ventilator respiratory support.

Other Neuromuscular Disease

Nutritional impairment, diminished respiratory function, or rapidly progressive symptoms in 12 months:

- Loss of ambulation
- Loss of speech
- Diet change
- Total care or life-threatening complications (infections such as respiratory, urinary, sepsis, fever)
- Pressure ulcer Stage 3-4

Cancer

- Malignancy with aggressive disease, distant metastasis at presentation, or progressive disease developed during treatment
- Refusal of further tumor-specific treatment

→ In general, a patient with metastatic solid cancer, acute leukemia, or high-grade lymphoma, who will not be receiving systemic chemotherapy (for any reason), has a prognosis of less than 6 months, except in the case of breast or prostate cancer.

Debility

***Only use as a secondary diagnosis** **There must be an alternate primary diagnosis.*

At least one of the following in the last 12 months:

- Aspiration pneumonia
- Septicemia
- Recurrent fever
- >10% weight loss in 6 months
- Pressure ulcer Stage 3-4
- Insufficient food/fluid intake
- PPS ≤ 50% (see pages 10-11)

Supportive findings:

- Significant dysphagia
- Albumin < 2.5 g/dL

End-Stage Dementia

- FAST Score 7C or worse (see page 16) or use Mitchell Mortality Risk Index for Dementia (see page 17)

PLUS one of the following in the last 12 months:

- Aspiration pneumonia
- Upper tract UTI
- Sepsis
- Pressure ulcer stage 3-4
- Fever
- Weight loss of >10% in 6 months
- Albumin < 2.5 g/dL

Heart Disease or CHF

- Patient on maximal medical therapy, including diuretics, beta blockers, and afterload reducers, with clinical signs of NYHA Class III-IV (see page 17)
- CHF, angina, or worsening/difficult-to-manage edema
- EF < 20% is helpful but not mandatory
- Usually have AICD turned off, but may allow pacemaker to continue.

HIV

Both:

1. CD4+ count < 25 cells/mcL or persistent viral load > 100,000 copies/mL
2. PPS ≤ 50% (see pages 10-11)

Supportive Findings:

HIV

Both:

1. CD4+ count < 25 cells/mcL or persistent viral load > 100,000 copies/mL
2. PPS ≤ 50% (see pages 10-11)

Supportive findings:

- Diarrhea > 1 year
- Albumin < 2.5 g/dL
- > 50 y/o
- CHF
- Advanced liver disease
- Resistance to anti-retroviral, chemo, or prophylactic drug therapy

→ *No patient with AIDS should be considered end-stage until a physician with expertise in HIV treatment has thoroughly evaluated the patient's condition.*

Liver Disease

Both:

1. PT/INR > 1.5 & Albumin < 2.5 g/dL
2. Advanced liver symptoms/signs:

- Refractory ascites
- Spontaneous bacterial peritonitis
- Hepatorenal syndrome
- Hepatic encephalopathy
- Recurrent variceal bleeding

Supportive findings:

- Cachexia
- Continued ETOH use
- Portal HTN
- Hepatitis B or C

→ 3 Month Mortality based on MELD Score (Mayo Clinic MELD Calculator):

- 20-29: 56%
- 30-39: 76.5%
- Over 40: 98.2%

Multiple Sclerosis

- Nutritional impairment (insufficient intake, weight loss, dehydration) **OR**
- Rapidly progressive in 12 months:
  - Losses in ambulation
  - Loss of speech
  - Diet change
  - ADLs

Life-threatening complications within 12 months, such as:

- Infections (especially lower respiratory tract, urinary tract, sepsis)
- Pressure ulcer (stage 3 or 4)
- Dyspnea

Parkinson's Disease

Progression of disease in 12 months with losses in:

- Ambulation
- Speech
- Diet
- ADLs
- Nutritional impairment: weight loss, insufficient intake, declines in artificial hydration/feeds

Supportive clinical findings:

- Respiratory compromise
- Infectious complications of the lower respiratory tract, urinary tract, or sepsis
- Pressure ulcer stage 3-4

Pulmonary Disease

Both:

1. Severe symptoms of dyspnea at rest or minimal activity:
   - Fatigue
   - Cough
   - Decreased functionality
   - Increased ER/hospital visits
2. Hypoxemia at rest on room air

Supportive findings:

- Right-sided CHF
- Cor pulmonale
- Weight loss of >10% in 6 months
- Resting tachycardia
- Other: increased dependence, depression, no spouse, co-morbid conditions

Renal Disease

1. Discontinuing dialysis or not seeking dialysis or a transplant for renal failure

PLUS

2. Cr clearance <10 ml/min (<15 ml/min if diabetic) or <15 ml/min if CHF

OR

3. Cr > 8.0 mg/dL (>6 mg/dL if diabetic)
4. Lower Cr levels may be considered with other significant diseases

Supportive signs/symptoms:

- Uremia
- Oliguria
- Hyperkalemia
- Uremic pericarditis
- Hepatorenal syndrome
- Fluid overload

→ Supportive co-morbid conditions: advanced disease of respiratory, CV, or GI systems.

Stroke

- PPS ≤ 40% (see pages 10-11)
- Nutritional impairment:
  - Weight loss > 10% in 6 months
  - Albumin < 2.5 g/dL
  - Aspiration
  - Inadequate intake
  - Dysphagia
  - History of recurrent fever, sepsis, pneumonia, UTI
  - Dyspnea

→ If acute, usually comatose for three days, anoxic encephalopathy with seizures, dysphagia, and no artificial nutrition/hydration planned or continued ventilator support.

Coma

Comatose patient with any **3** of the following **on day 3 of coma** (may be due to trauma, stroke, anoxic brain injury, or bleeds):

- Abnormal brain stem response
- Absent verbal response
- Absent withdrawal response
- Cr > 1.5 mg/dL

IN ALL CASES

A physician may determine that a patient has a life expectancy of six months or less, even if the findings outlined for any of the above diseases are not present.

Artificial Nutrition and Hydration (ANH) in End-of-Life Care

At the end of life, many patients lose their desire to eat or drink, signaling that their body is slowing down and can no longer process nutrition.

What is ANH?

ANH provides food and fluids via tube or IV when patients cannot eat or drink. However, at the end of life, it can lead to discomfort and complications, including:

- Abdominal bloating, cramps, reflux
- Difficulty breathing (fluid buildup)
- Pressure ulcers
- Diarrhea
- Pneumonia (aspiration risk)

Refusing or Discontinuing ANH

Patients have the right to refuse or discontinue ANH if it no longer benefits their comfort. This is not considered suicide but a choice to forgo a treatment that cannot restore health.

Legal Considerations in Michigan

In Michigan, ANH may be refused under an advance directive if the patient is no longer able to make decisions. A witnessed advance directive is legally honored.

Source: *Caring Connections, National Hospice and Palliative Care Organization.*

Non-Disease Specific Prognostic Factors

Patients with a documented decline in clinical status may have a life expectancy of six months or less if there is **documented progression** of worsening clinical status, symptoms, signs, and/or laboratory results. No specific number of variables must be met, but these factors apply when decline i**s not considered reversible.**

Clinical Course

Documented progression of:

- Recurrent/intractable infection
- Progressive inanition
- Dysphagia

Symptoms (Severe, worsening, or intractable)

- Dyspnea
- Cough
- Nausea/vomiting (N/V)
- Diarrhea
- Pain

Signs

- Hypotension
- Ascites
- Venous, arterial, or lymphatic obstruction
- Edema

Non-Disease Specific Prognostic Factors Cont'

- Pleural/pericardial effusion
- Generalized/progressive weakness
- Change in level of consciousness (LOC)

Supportive Laboratory Findings

- O_2 saturation, CO_2, Ca^{2+}, Cr, LFTs, tumor markers, sodium, potassium, albumin, Hgb/Hct, BUN/Cr

Additional Indicators of Decline

- PPS ≤ 50% (see pgs. 10-11)
- Dementia FAST Score 7C or worse (see pg. 8)
- Stage 3-4 pressure ulcer
- Increased ER/hospital/office visits
- Significant comorbid conditions: COPD, CHF, CAD, DM, CVA, ALS, MS, Parkinson's, ARF/CRF, liver disease, cancer, AIDS/HIV, dementia

Functional Assessment Staging (FAST) Score for Alzheimer's Dementia

- 7A – Unable to say six distinct, intelligible words in a day
- 7B – Babbling
- 7C – Chair-bound; loss of ambulation
- 7D – Unable to hold self up in chair
- 7E – Loss of smile
- 7F – Unable to hold up head (floppy head/neck)

New York Heart Association (NYHA) Functional Classification

- **Class I:** No limitation of activities; no symptoms from ordinary activities.
- **Class II:** Slight limitation of activity; comfortable at rest or with mild exertion.
- **Class III:** Marked limitation of activity; comfortable only at rest; symptoms occur with ordinary activity.
- **Class IV:** Confined to bed or chair; any physical activity causes discomfort; symptoms occur at rest.

Mitchell Mortality Risk Index for Dementia

Points	Risk Factor
1.9	Complete dependence with ADLs
1.9	Male gender
1.7	Cancer
1.6	Congestive heart failure
1.6	O_2 therapy needed within 14 days
1.5	Shortness of breath
1.5	<25% of food eaten at most meals
1.5	Unstable medical condition
1.5	Bowel incontinence
1.5	Bedfast
1.4	Age > 83 years
1.4	Not awake most of the day

Risk Estimate of Death Within 6 Months

Score	Risk %
0	8.9%
1 - 2	10.8%
3 - 5	23.2%
6 - 8	40.4%
9 - 11	57.0%
≥12	70.0%

Palliative Performance Scale (PPS) – Version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work; No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work; Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity with effort; Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable to perform normal job/ work; Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable to perform hobbies/ housework; Significant disease	Occasional assistance necessary	Normal or reduced	Full or confused
50%	Mainly sit/lie	Unable to do any work; Extensive disease	Considerable assistance required	Normal or reduced	Full or confused
40%	Mainly in bed	Unable to do most activities; Extensive disease	Mainly assistance	Normal or reduced	Full, drowsy, or confused
30%	Totally bed bound	Unable to do any activity; Extensive disease	Total care	Normal or reduced	Full, drowsy, or confused
20%	Totally bed bound	Unable to do any activity; Extensive disease	Total care	Minimal intake, sips only	Full, drowsy, or confused
10%	Totally bed bound	Unable to do any activity; Extensive disease	Total care	Mouth care only	Drowsy or coma, +/- confusion
0%	Death	-	-	-	-

Instructions for Use of PPS *(Copyright 2001 Victoria Hospice Society)*

1. Determining PPS Scores

- PPS scores are determined by reading horizontally at each level to find the best fit for the patient, which is then assigned as the PPS% score.
- Begin at the left column and read downward until the appropriate ambulation level is reached, then read across to the next column and downward again until the activity/evidence of disease is located.
- Repeat these steps for all five columns before assigning the actual PPS score.
- Leftward columns (those further to the left) are stronger determinants and generally take precedence over others.

2. Example Application

- A quadriplegic patient requiring total care would be assigned PPS 30%.
- Although this patient may be placed in a wheelchair (which might initially suggest PPS 50%), the score remains 30% because the patient would otherwise be totally bedbound without caregivers providing total care, including lift/transfer.
- The patient may have normal intake and full consciousness.
- However, if a paraplegic patient is bedbound but still capable of some self-care (e.g., feeding themselves), the PPS would be higher at 40% or 50%, since they are not considered “total care.”

Instructions for Use of PPS Cont' *(Copyright 2001 Victoria Hospice Society)*

3. Scoring Considerations

- PPS scores are assigned in 10% increments only.
- If different columns suggest slightly different levels, a "best fit" decision must be made.
- Choosing a half-fit value (e.g., PPS 45%) is not correct.
- The combination of clinical judgment and leftward precedence determines whether 40% or 50% is the more accurate score.

4. Uses of PPS

- PPS serves as an effective communication tool to describe a patient's current functional level.
- It may be useful for workload assessment, measurements, and comparisons.
- PPS also appears to have prognostic value in patient care planning.

Online Resources

- FAST FACTS – www.mypcnow.org/fast-facts
  Excellent, short articles with practical insights on numerous searchable topics.
- e-Prognosis – www.eprognosis.org
  Web-based calculator for prognosis of various conditions.
- GlobalRPh – www.globalrph.com
  Useful medication website for reviewing meds and calculating doses.
- Pallimed Blog – www.pallimed.org
  Blog by leaders in palliative medicine and hospice, offering input on current research and commentary.
- Medscape Hospice & Palliative Medicine – www.medscape.com/resource/hospice/
  Comprehensive resource with links to articles on hospice and palliative care.
- Palliative Doctors – www.palliativedoctors.org
  Public website about palliative care, including a provider directory and educational materials.
- Get Palliative Care – www.getpalliativecare.org
  Access a palliative care provider directory and educational materials.
- Center to Advance Palliative Care (CAPC) – www.capc.org
  Website for healthcare professionals, offering resources, training, & palliative care tools.

Notes

Notes

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