Big Bend Hospice

CELEBRATING 40 YEARS

your hometown hospice, licensed since 1983

QUICK REFERENCE GUIDE

for Hospice Diagnosis

Inspiring hope by positively impacting the way our community experiences serious illness or grief - one family at a time.

HOSPICE INDICATORS

This booklet is intended to help families and clinicians determine how hospice is appropriate for each disease. We have included the diagnoses we see most commonly as well as co-morbidities to consider showing increased decline.

- Multiple ER visits/hospitalizations
- Difficulty with pain control
- Shortness of breath/ oxygen dependence
- Maximum to total assist with all ADLs
- Unexplained, progressive weight loss >-5% in the past 30 days or 10% in the past 6 months *(enteral feedings: >=10% in the past 6 months)*
- Multiple co-morbidities including increased infections
- Progression of disease as documented by worsening clinical status, symptoms, signs and laboratory results
- Serum albumin < =2.5 gm/dL
- Palliative Performance Scale < 50%
- Progressive stage 3-4 decubitus ulcers despite optimal care and treatment
- Life expectancy < 6 months
- Progressive decrease in response to medical modalities

TABLE OF CONTENTS

WHEN IS IT TIME TO THINK ABOUT HOSPICE?

- Patients or families call more with questions regarding care.
- When there is an increase in existing symptoms.
- The patient has had two or more hospitalizations within the last year due to chronic illness.
- When your patient is diagnosed with a life limiting illness.
- When patients or families appear to be transitioning from curative care to comfort care.
- When families are no longer able to care for end stage patients.
- When you notice a sudden worsening of your patient's condition or loss of abilities.
- Dependence of 3 of 6 Activities of Daily Living
  - Bathing - Dressing - Feeding
  - Transfers - Continence of urine and stool - Ambulation

Would you be surprised by this patient's death within the next six months?
CALL (850) 878-5310

SYMPTOMS REQUIRING GIP LEVEL OF CARE

- Poorly Controlled Pain
- New or Worsening:
  - Agitation - Restlessness - Anxiety - Delirium
- Dyspnea/Unmanaged Respiratory Distress
- Uncontrolled Nausea/Vomiting *(bowel obstruction)*
- Seizures Current or Anticipated
- Patient requires frequent repositioning requiring more than one person *(i.e. pathologic fracture or trauma fracture nonrepairable)*
- Open lesions requiring frequent skilled care, dressing changes *(i.e.decubitus, malignant ulcerations, fistulas, etc)*
- Inability to Manage Secretions
- Complicated-technical delivery of medication *(lack of oral/SL route)* i.e requires IV meds
- Sudden deterioration requiring intensive nursing intervention *(this relates to terminal extubation as an example maybe link)*
- Terminal extubation *(removal for mechanical ventilation or non-invasive ventilation/Bipap requires frequent RN assessment/intervention/med titration)*
- OTHER *(i.e. psycho-social)*

DEMENTIA
Guidelines for End-Stage Alzheimer's Disease and Related Disorders

- The patient is severely demented
- Recent decline in functional status: PPS < 50%
- Dependence in 3 of 6 ADLS such as bathing, dressing, feeding, transfers, continence & ambulation.
- Unintentional, progressive weight loss of 10% over the past 6 months.
- Symptomatic condition or secondary conditions as evidenced by:
- Ability to speak is limited to 6 intelligible words or fewer in the course of a day or an intensive interview.
- Unable to consistently or reliably make their needs known.
- The patient has had one or more of the following medical complications related to dementia during the past year
- Aspiration pneumonia.
- Upper urinary tract infection.
- 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.
- Comorbid or other event indicating high probability of death in six months.
- See page 23 for FAST Scale

HOW WE HELP: ALZHEIMER'S & RELATED DISORDERS

- **Ongoing education with family and caregivers about disease progression to reduce emergency room visits.**
- **Help with symptom management, agitation, safety issues.**
- **Respite care as needed.**
- **Coordination of treatments for co-morbidities as patient can handle.**
- **Support and connection to community resources for caregivers.**
- **Spiritual care for family and patient.**

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LIFE LIMITING CONDITION AS EVIDENCED BY:

- Documentation of clinical progression of disease evidenced by:
  - Physician assessment
  - Laboratory studies
  - Multiple ER visits
  - Inpatient hospitalizations

AND/OR

- PPS 70% or less
  - Radiologic or other studies
- Dependence in 3 or 6 Activities of Daily Living (ADLS) such as bathing, dressing, feeding, transferring, continence, ambulation.
- Unintentional, progressive weight loss of 10% of total body weight over the past 6 months.
- Serum albumin <2.5gm/dl
  (may be helpful prognostic indicator but should not be considered alone)

GENERAL INDICATORS:

- Patient/family desires no further aggressive medical intervention including acute care hospitalization.
- Has diagnosed and medically documented metastatic disease.
- Active co-morbidity accelerating the trajectory of the terminal illness.
- Progressive symptoms despite medical intervention and evidence of decline medically documented such as:
  - Increasing tumor mass
  - Recurrence of disease
  - Stage of tumor
  - Failure or declination of chemotherapy/radiation.

HOW WE HELP: END STAGE CANCER

- Educational and emotional support regarding cessation of treatment.
- Aggressive pain management and education with patient and family about what to expect with progression of illness.
- Use of palliative treatments to relieve symptoms as appropriate
- Nutritional counseling as requested by family and patient.
- Coordination of comfort measures for patient, including durable medical equipment and non-medical therapies.
- Psychosocial and bereavement support for patient and family.
- Caregiver support.
- Spiritual support for patient and family.
- Connection with community resources as necessary.

CORE INDICATORS:

- In the physician's clinical judgment, the patient has a terminal condition of 6 months or less if the disease follows its usual course.
- Documentation of End Stage Disease is present.
- The patient/family is informed of the life-limiting condition and choose palliative care. Recent impaired functional and/or nutritional status.

AS EVIDENCED BY:

- A Palliative Performance Scale of < 40; mainly in bed, mostly requiring assistance with self-care
- One of the following MUST be present and documented in Medical Record:
  - Weight loss > 10% during the previous 6 months
  - Weight loss > 7.5% in previous 3 months
  - Current history of pulmonary aspiration without effective response to speech language pathology interventions
  - Serum Albumin < 2.5 gm/dl
  - Calorie counts documenting inadequate caloric/fluid intake

HOW WE HELP: STROKE

- **Comfort Care and pain control for those in persistent vegetative state.**
- **Management of feeding tubes as requested by family or patient if dysphagia is a concern.**
- **Pain relief related to muscle contractures, constipation, bed sores, and infections.**
- **Support & education for family and patient as treatments are withdrawn.**
- **Support for caregivers regarding neurological changes.**
- **Spiritual care for family and patient as needed.**

LIFE LIMITING CONDITION AS EVIDENCED BY:

- Exam by a neurologist within 3 months of assessment for hospice is advised to assist with prognosis.
- Two factors determining prognosis:
  - Ability to breath
  - Ability to swallow

AND/OR

- Dyspnea at rest
- Vital Capacity less than 30% of normal
- Rapid progression of ALS occurring within the 12 months preceding
- Wheelchair or bedbound
- Recurrent fever after antibiotic therapy
- Assistance with all ADLs
- Recurring aspiration pneumonia
- Sepsis
- Upper urinary tract infections
- Barely intelligible speech
- Stage 3 or 4 decubitus ulcers
- Declines artificial ventilation *(external ventilation used for comfort measures only)*
- Critically impaired nutritional status occurring within the 12 months preceding

GENERAL INDICATORS:

- Patient/family desires no further aggressive medical intervention including acute care hospitalization.
- Progressive symptoms despite medical intervention and evidence of decline medically documented such as:
- Increased weakness or impairment in mobility;
- Active co-morbidity accelerating the trajectory of the terminal illness.

HOW WE HELP: ALS

- **Assistance in respiratory insufficiency care including respiratory support management.**
- **Nutrition and hydration support as requested by patient.**
- **Help with speech and communication modalities as possible.**
- **Coping with depression and pseudobulbar affect.**
- **Aggressive pain management.**
- **Psychosocial support for patient and the family.**
- **Spiritual care and support for the patient and the family.**

PULMONARY DISEASE
Guidelines for End-Stage Pulmonary Disease and Related Disorders

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LIFE LIMITING CONDITION AS EVIDENCED BY THE FOLLOWING SYMPTOMS:
- Dyspnea at rest and on exertion
- Severe cough
- Copious/purulent sputum

SIGNS:
- Cyanosis: blue lips, fingertips
- Retractions
- Oxygen dependent
- Depressed diaphragm
- Accessory muscles of respiration
- Pursed-lip breathing
- Wheezing
- Recurrent infections
- Poor response to bronchodilators
- Diminished breath sounds
- Pulmonary hyperinflation: barrel-chested
- Increased visits to Emergency Department
- Increased expiratory phase: slowed forced expiration
- Increased hospitalization 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
- Forced expiratory volume in one second *(FEV1)* after bronchodilator, less than 30% of predicted*

EVIDENCED BY:
- Echocardiographic documentation
- Chest x-ray
- EKG*
- Physical signs of RHF
- Hypoxemic at rest on supplemental oxygen
- 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.*

HOW WE HELP: PULMONARY DISEASE
- **Increased quality of life**
- **Medication to relieve nausea, pain or shortness of breath**
- **Coordination of comfort measures for patient including durable medical equipment and non-medical therapies**
- **Education for the patient and family as disease progresses.**
- **Psychosocial support for patient and the family**
- **Spiritual care and support for the patient and the family.**

LIVER DISEASE

Guidelines for End-Stage Liver Disease and Related Disorders

Would you be surprised by this patient's death within the next six months?

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THE PATIENT SHOULD MEET THE FOLLOWING CRITERIA:

- Life limiting condition
- Pt/family elected palliative care
- Pt/family informed condition is life limiting
- Documentation of clinical progression of disease as evidenced by:
  - Serial physician assessment
  - Laboratory studies
  - Inpatient hospitalizations
  - Radiologic or other studies
  - Multiple Emergency Department visits
- Dependence of 3 of 6 Activities of Daily Living
  - Bathing
  - Dressing
  - Feeding
  - Transfers
  - Ambulation
  - Continence of urine and stool

PATIENT IS NOT A CANDIDATE FOR LIVER TRANSPLANTATION.

- Laboratory indicator of severely impaired liver function should show both:
  - Prothrombin time prolonged more than 5 sec. over control.
  - Serum albumin less than 2.5 gm/dl.

GENERAL INDICATORS:

- Ascites, persistent
- Spontaneous bacterial peritonitis
- Hepatorenal syndrome
- Hepatic encephalopathy
- Recurrent variceal bleeding

SUPPORTING FACTORS

- Progressive malnutrition and/or:
  - Muscle wasting with weakness
  - Continued active alcoholism
  - Hepatocellular carcinoma
  - Hepatitis B infection
  - Hepatitis C infection
  - Refractory to treatment

HOW WE HELP: END STAGE LIVER DISEASE

- Increased quality of life by managing symptoms.
- Pain management specifically to avoid exacerbation of encephalopathy.
- Coordination of care for comorbidities.
- Aggressively managing distressing symptoms to reduce hospitalizations.
- Nutritional support.
- Supporting the family with psychosocial and spiritual support including substance abuse issues.
- Education for the patient and family as disease progresses.

LIFE LIMITING CONDITION AS EVIDENCED BY:

- Documentation of clinical progression of disease evidenced by:
  - Physician assessment
  - Multiple ER visits & Inpatient hospitalizations
  - Laboratory studies
  - Radiologic or other studies

AND/OR

- The patient is already optimally treated with diuretics and vasodilators, which may include:
  - Angiotensin-converting enzymes (ACE) inhibitors or the combination of hydralazine and nitrates. If side effects, such as hypotension or hyperkalemia, prohibit the use of ACE inhibitors or the combination of hydralazine and nitrates, this must be documented in the medical records.

    -or-
  - Patient is having angina pectoris, or dyspnea with minimal exertion, resistant to standard nitrate therapy & are either not candidates or decline invasive procedures.
- Symptoms may present at rest.
- The patient has significant symptoms of recurrent congestive heart failure *(CHF)* despite optimal treatment.

- If any physical activity is undertaken, symptoms are increased.

DOCUMENTATION OF THE FOLLOWING FACTORS MAY PROVIDE ADDITIONAL SUPPORT FOR END-STAGE HEART DISEASE:

- Treatment resistant symptomatic supraventricular or ventricular arrhythmias
- Documentation of ejection fraction of 20% or less
- History of cardiac arrest or resuscitation
- History of unexplained syncope
- Brain embolism of cardiac origin
- Concomitant HIV disease

HOW WE HELP: HEART DISEASE

- Increased quality of life
- Medication to relieve symptoms such as pain or shortness of breath
- Coordination of comfort measures for patient including durable medical equipment and non-medical therapies
- Education for the patient and family as disease progresses.
- Psychosocial support for patient and the family
- Spiritual care and support for the patient and the family.

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LIFE LIMITING CONDITION AS EVIDENCED BY:

- Creatinine Clearance < 10cc/min. *(15cc/ for diabetics).*
- Serum creatinine > 8.0 md/dL *(6.0 mg/dL for diabetics).*
- Estimated glomerular filtration rate *(GFR)* < 10 ml/min.
- Discontinues or refuses dialysis.

SECONDARY CONDITIONS:

- Fluid overload, dyspnea
- Hypoalbuminemia
- Mechanical ventilation
- Malignancy
- Electrolyte abnormalities
- Chronic lung disease
- Advanced CHF
- Advanced liver disease
- Immunosuppression/AIDS
- Albumin < 3.5 gm/dL
- Platelet count < 25,000
- GI bleeding
- Uremia
- Hyperkalemia
- Uremic pericarditis
- Hepatorenal syndrome
- Oliguria < 400cc/ 24 hours
- Intractable fluid overload

HOW WE HELP: END STAGE RENAL DISEASE

- **Emotional and spiritual support.**
- **Management of pain and symptom relief.**
- **Education regarding progression of decline post dialysis cessation.**
- **Comfort care for congestion, restlessness, mental changes.**
- **Emotional support for family as disease progresses.**
- **Spiritual support for family and patient.**

PPS SCALE
Palliative Performance Scale and Hospice

LEVEL	AMBULATION	ACTIVITY AND EVIDENCE OF DISEASE	SELF-CARE	INTAKE	CONSCIOUS LEVEL
100%	Full	Normal Activity and Work No Evidence of Disease	Full	Normal	Full
90%	Full	Normal Activity and 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 do Normal Job or Work Significant Disease	Full	Normal or reduced	Full
60%	Reduced	Unable to do Hobby or Housework Significant Disease	Occasional Assistance Necessary	Normal or reduced	Full or confusion
50%	Mainly Sit/Lie	Unable to do any Work Extensive Disease	Considerable Assistance Necessary	Normal or reduced	Full or confusion
40%	Mainly in Bed	Unable to do Most Activities Extensive Disease	Mainly Assistance	Normal or reduced	Full or drowsy +/- confusion
30%	Totally Bed Bound	Unable to do any Activity Extensive Disease	Total Care	Normal or reduced	Full or drowsy +/- confusion
20%	Totally Bed Bound	Unable to do any Activity Extensive Disease	Total Care	Minimal to sips	Full or drowsy +/- confusion
10%	Totally Bed Bound	Unable to do any Activity Extensive Disease	Total Care	Mouth care only	Drowsy or coma +/- confusion
0%	Death	-	-	-	-

SERVICE AREA

Our services area covers Franklin, Gadsden, Jefferson Madison, Leon, Liberty, Taylor, & Wakulla Counties.

Big Bend Hospice is available 24 hours, 7 days a week

PLEASE CALL (850) 878-5310

for assistance with family/patient hospice education or our referral process.

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 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: Improperly putting on clothes without assistance or cueing *(e.g., may put street clothes on overnight clothes, or put shoes on wrong feet, or have difficulty buttoning clothing)* occasionally or more frequently over the past weeks.

Urinary incontinence. *(occasionally or more frequently over the past weeks.)*

Fecal incontinence. *(occasionally or more frequently over the past weeks.)*

Unable to bathe properly. *(e.g., difficulty adjusting bath water temperature)* occasionally or more frequently over the past weeks. Inability to handle mechanics of toileting. *(e.g., forgets to flush the toilet, does not wipe properly or properly dispose of toilet tissue)*

7: 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.

Speech ability is limited to the use of a single intelligible word in an average day of in the course of an intensive interview. *(the person may repeat the word over and over.)*

Ambulatory ability is lost.

Cannot sit up without assistance. *(e.g. the individual will fall over if there are not lateral rests [arms] on the chair.)*

Loss of ability to smile.

Loss of ability to hold head up independently.

(Patient becomes hospice appropriate.)

VETERAN SERVICES
Veterans Supporting Veterans

Big Bend Hospice is proud to provide care that recognizes the challenges unique to military families. As a member of the National We Honor Veterans program, we reached the highest partner level – Five Stars – by offering:

- A Veteran Liaison to provide assistance to Veterans at the end of life.
- Veterans Memorial Garden to pay tribute to U.S. military Veterans.
- Services to dedicate pavers purchased in in honor of Veterans.
- Complimentary dog tags for every Veteran in our care: one displayed on the Valor Tree and one given to the family.
- Vet-to-Vet visits to provide camaraderie by a peer.
- Valor Ceremonies to honor Veterans in our care.

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We Honor Veterans ★★★★★

AmeriCorps

volunteerflorida

If you have a Veteran who may benefit from Hospice Care,
PLEASE CALL (850) 878-5310
for assistance with family/patient hospice education or our referral process.

MAKING A REFERRAL IS EASY

TO GET STARTED CALL BIG BEND HOSPICE AT (850) 878-5310 OR SUBMIT THE REFERRAL ONLINE BY SCANNING THE QR CODE OR VISITING WWW.BIGBENDHOSPICE.ORG/MAKE-A-REFERRAL

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