# NAVIGATING THE FINAL JOURNEY: PROGNOSTICATION AND THE HOSPICE EXPERIENCE

SAUL RIVARD, MD

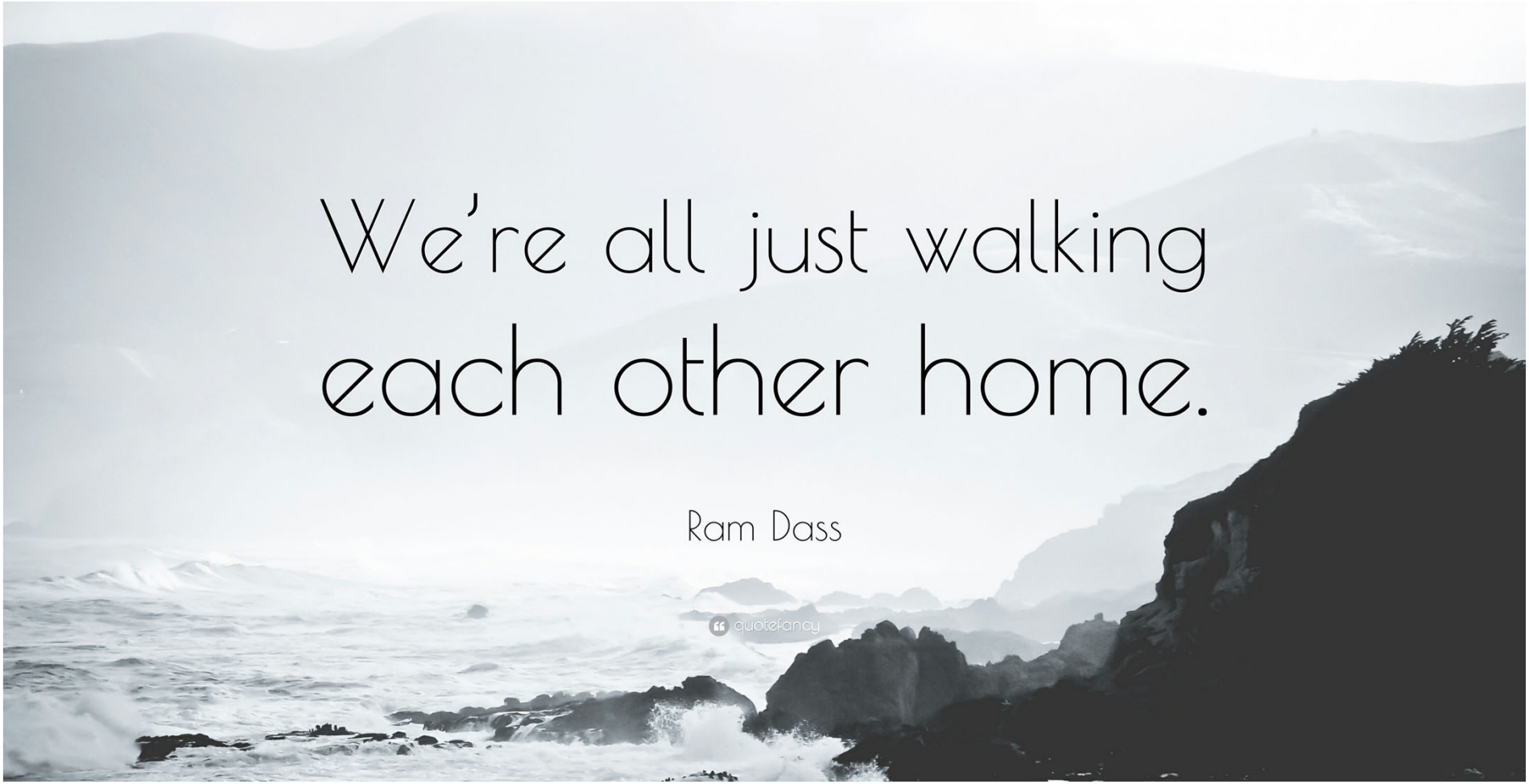
BIG MOUNTAIN MEDICAL CONFERENCE

# DISCLOSURES

- I HAVE NO FINANCIAL DISCLOSURES NOR CONFLICTS OF INTREST TO DISCLOSE

# OBJECTIVES

- Define hospice care.
- Identify the components of hospice.
- Define hospice eligibility requirements.


We're all just walking
each other home.
Ram Dass
quotefancy

# WHAT IS HOSPICE CARE?

- Considered to be the model for quality, compassionate care for people facing a serious or life-limiting illness or injury, hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well.

# MEDICARE HOSPICE BENEFIT (MHB)

- MHB was created to assist families in caring for their terminally ill loved ones at home.
- Patient-elected benefit. Turns off Medicare part A. Patient can also revoke hospice.
- Hospice agency becomes responsible for Plan of Care and receives a per diem payment.
- It offers 24/7 on-call services from a trained hospice nurse, but *does not* provide round-the-clock custodial care.
- There is no maximum duration of time for reimbursement under the MHB.
- Most states have a Medicaid benefit that mirrors MHB.
- Most private insurances have a hospice benefit, services may vary between plans.

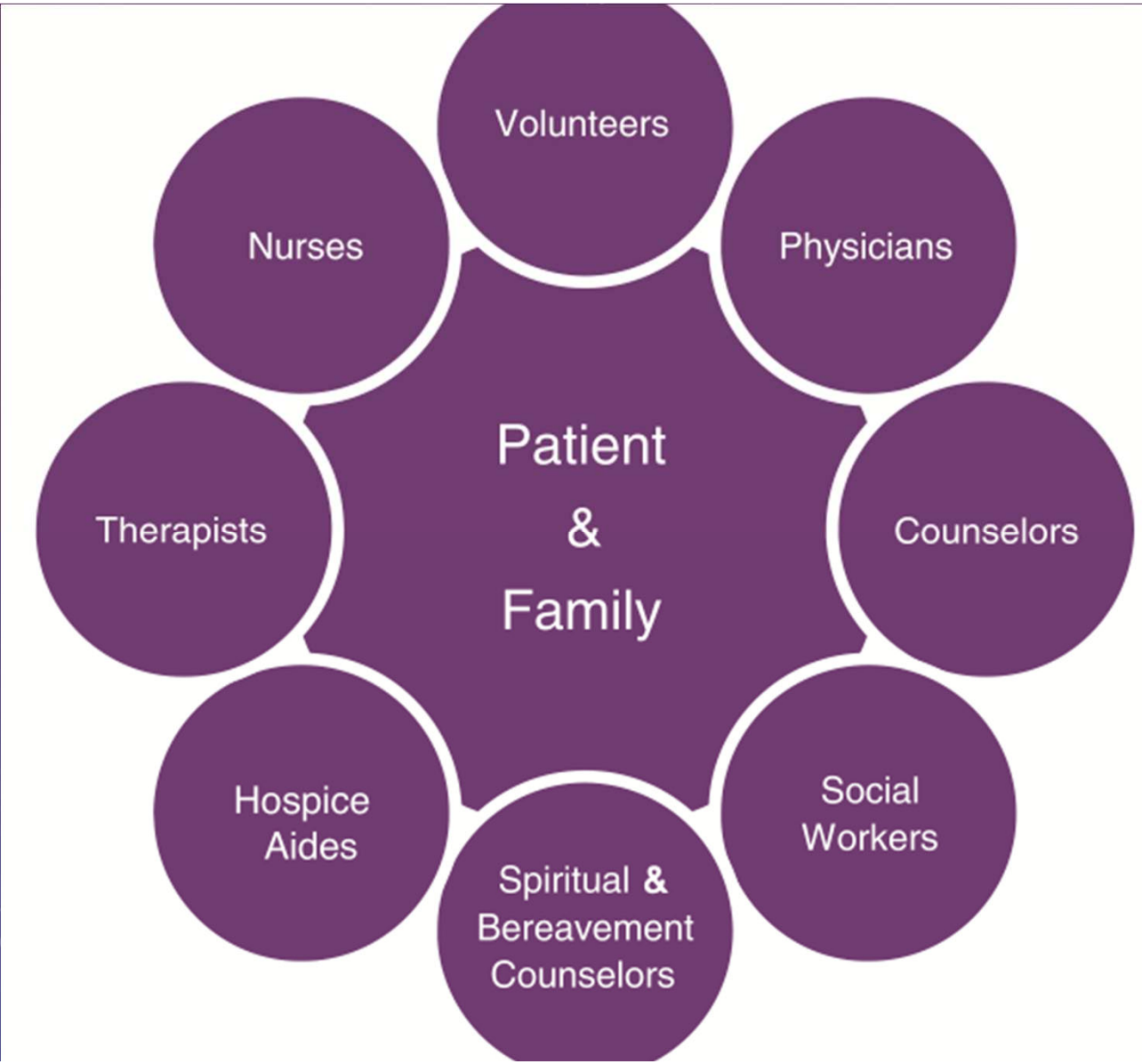
# MEDICARE HOSPICE BENEFIT (MHB), CONT.

- Eligibility Requirements:
  - A physician must certify a prognosis of six months or less, assuming “the terminal illness runs its usual course.”
  - The focus of treatment is palliative instead of curative.
- Individual hospice agencies may have additional criteria for admission, for example:
  - No current or anticipated use of blood products, artificial hydration, TPN, or non-oral feeding.
  - A primary caregiver must be present in the home most, if not all, of the time.

# BARRIERS TO HOSPICE REFERRALS

- Healthcare professionals concerned about being wrong (there is no penalty if patient survives >6 months).
- No hospice agency nearby, especially in rural areas.
- The word/idea of hospice is scary for patients and/or their families.

# HOSPICE TEAM



# ITEMS AND SERVICES INCLUDED IN MHB

Services from a hospice-employed physician, nurse practitioner (NP), or other physicians chosen by the patient

Nursing care

Medical equipment

Medical supplies

Drugs to manage pain and symptoms

Hospice aide and homemaker services

Physical therapy

Occupational therapy

Speech-language pathology services

Medical social services

Dietary counseling

Spiritual counseling

Individual and family or just family grief and loss counseling before and after the patient's death

Short-term inpatient pain control and symptom management and respite care

# SERVICES PROVIDED

- Manages the patient's pain and other symptoms
- Assists the patient and loved ones with the emotional, psychosocial, and spiritual aspects of dying
- Provides medications and medical equipment
- Instructs the informal caregivers on how to care for the patient
- Provides grief support and counseling to the patient as well as the surviving family and friends for up to 13 months after death
- Makes short-term inpatient care available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time
- Delivers special services like speech and physical therapy, when needed

# LOCATION OF CARE

- Most hospice care is delivered in the patient's own home.
- This encompasses not just private residences, but also nursing homes, assisted living facilities, and other residential settings.
- Hospice services may additionally be offered in dedicated hospice centers and hospitals.

# LEVELS OF CARE

**Routine Home Care (RHC)** is the most common level of hospice care. With this type of care, an individual has elected to receive hospice care at their residence.

**Continuous Home Care (CHC)** is care provided for between eight and 24 hours a day to manage pain and other acute medical symptoms. CHC services must be predominately nursing care, supplemented with caregiver and hospice aide services intended to maintain the terminally-ill patient at home during a pain or symptom crisis.

**Respite Care (also referred to as Inpatient Respite Care (IRC))** is available to provide temporary relief to the patient's primary caregiver. Respite care can be provided in a hospital, hospice facility, or a long-term care facility with enough 24-hour nursing personnel present.

**General Inpatient Care (GIP)** is provided for pain control or other acute symptom management that cannot feasibly be provided in any other setting. GIP begins when other efforts to manage symptoms are not sufficient. GIP can be provided in a Medicare certified hospital, hospice inpatient facility, or nursing facility with a registered nursing available 24 hours a day to provide direct patient care.

| Rank | International Classification of Diseases, Tenth Revision (ICD-10)/ Reported Principal Diagnosis" | | Number of Beneficiaries | Percentage of all Reported Principal Diagnoses |
|---|---|---|---|---|
| 1 | G311 | Senile degeneration of brain, not elsewhere classified | 132,665 | 7.7 |
| 2 | G309 | Alzheimer's disease, unspecified | 115,336 | 6.7 |
| 3 | J449 | Chronic obstructive pulmonary disease, unspecified | 74,178 | 4.3 |
| 4 | G301 | Alzheimer's disease with late onset | 61,097 | 3.5 |
| 5 | G20 | Parkinson's disease | 50,977 | 2.9 |
| 6 | I509 | Heart failure, unspecified | 46,806 | 2.7 |
| 7 | I2510 | Atherosclerotic heart disease of native coronary artery w/o angina pectoris | 43,159 | 2.5 |
| 8 | I672 | Cerebral atherosclerosis | 42,583 | 2.5 |
| 9 | C3490 | Malignant neoplasm of unspecified part of unspecified bronchus or lung | 40,948 | 2.4 |
| 10 | I110 | Hypertensive heart disease with heart failure | 36,776 | 2.1 |
| 11 | I679 | Cerebrovascular disease, unspecified | 35,699 | 2.1 |
| 12 | E43 | Unspecified severe protein-calorie malnutrition | 32,976 | 1.9 |
| 13 | I130 | Hypertensive heart & chronic kidney disease with heart failure and stage 1-4 or unspecified chronic kidney disease | 32,194 | 1.9 |
| 14 | I639 | Cerebral infarction, unspecified | 27,188 | 1.6 |
| 15 | C61 | Malignant neoplasm of prostate | 26,676 | 1.5 |
| 16 | N186 | End stage renal disease | 23,695 | 1.4 |
| 17 | J9601 | Acute respiratory failure with hypoxia | 22,129 | 1.3 |
| 18 | C259 | Malignant neoplasm of pancreas, unspecified | 21,678 | 1.3 |
| 19 | J441 | Chronic obstructive pulmonary disease w (acute) exacerbation | 18,992 | 1.1 |
| 20 | C189 | Malignant neoplasm of colon, unspecified | 18,372 | 1.1 |

***Source:*** *Hospice Analytics*

## Figure 15: CY 2021 days of care by length of stay, in days


***Source:*** *MedPAC July 2024 Data Book, Chart 11-15*

# CASE PRESENTATION

- Mr. Johnson is A 72 YO M with metastatic colon cancer and was recently admitted to your local hospital with sepsis. He does not have any further treatment options for his cancer. He was recently discharged and is seeing you today in clinic for follow up. His wife reports that Mr. Johnson has been spending more time sleeping, even prior to this admission, and now requires assistance bathing and dressing.

- Is Mr. Johnson eligible for hospice services?

## Palliative Performance Scale (PPS)

| 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 work Normal Job; Significant Disease | Full | Normal or reduced | Full |
| 60% | Reduced | Unable hobby/house work; Significant disease | Occasional assistance necessary | Normal or reduced | Full or Confusion |
| 50% | Mainly Sit/Lie | Unable to do any work; Extensive disease | Considerable assistance required | Normal or reduced | Full or Confusion |
| 40% | Mainly in Bed | Unable to do most activity; 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 | Totally Bed Bound | Mouth care only | Drowsy or Coma +/- Confusion |

# Functional Assessment Scale (FAST)

| | |
|---|---|
| 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 task, (e.g., planning dinner for guests, handling personal finances, such as forgetting to pay bills, etc.) |
| 5 | Requires assistance in choosing proper clothing to wear for the day, season or occasion, (e.g. pt may wear the same clothing repeatedly, unless supervised.* |
| 6 | Occasionally or more frequently over the past weeks. * for the following<br>**A)** Improperly putting on clothes without assistance or cueing .<br>**B)** Unable to bathe properly ( not able to choose proper water temp)<br>**C)** Inability to handle mechanics of toileting (e.g., forget to flush the toilet, does not wipe properly or properly dispose of toilet tissue)<br>**D)** Urinary incontinence<br>**E)** Fecal incontinence |
| 7 | **A)** Ability to speak limited to approximately ≤ 6 intelligible different words in the course of an average day or in the course of an intensive interview.<br>**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<br>**C)** Ambulatory ability is lost (cannot walk without personal assistance.)<br>**D)** Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests [arms] on the chair.)<br>**E)** Loss of ability to smile.<br>**F)** Loss of ability to hold up head independently. |

# DETERMINING PROGNOSIS

1. Progression of disease as documented by worsening clinical status, symptoms, signs and laboratory results
    a. Clinical Status
        i. Recurrent or intractable infections such as pneumonia, sepsis or upper urinary tract.
        ii. Progressive inanition as documented by:
            A. Weight loss not due to reversible causes such as depression or use of diuretics
            B. Decreasing anthropomorphic measurements (mid-arm circumference, abdominal girth), not due to reversible causes such as depression or use of diuretics
            C. Decreasing serum albumin or cholesterol
        iii. Dysphagia leading to recurrent aspiration and/or inadequate oral intake documented by decreasing food portion consumption.

# DETERMINING PROGNOSIS, CONT.

| Symptoms | Signs | Laboratory (When available. Lab testing is not required to establish hospice eligibility.) |
|---|---|---|
| • Dyspnea with increasing respiratory rate<br>• Cough, intractable<br>• Nausea/vomiting poorly responsive to treatment<br>• Diarrhea, intractable<br>• Pain requiring increasing doses of major analgesics more than briefly. | • Decline in systolic blood pressure to below 90 or progressive postural hypotension<br>• Ascites<br>• Venous, arterial or lymphatic obstruction due to local progression or metastatic disease<br>• Edema<br>• Pleural / pericardial effusion<br>• Weakness<br>• Change in level of consciousness | • Increasing $pCO_2$ or decreasing $pO_2$ or decreasing $SaO_2$<br>• Increasing calcium, creatinine or liver function studies<br>• Increasing tumor markers (e.g. CEA, PSA)<br>• Progressively decreasing or increasing serum sodium or increasing serum potassium |

# DETERMINING PROGNOSIS, CONT.

- Decline in Karnofsky Performance Status (KPS) or Palliative Performance Score (PPS) from <70% due to progression of disease.
- Increasing emergency room visits, hospitalizations, or physician's visits related to hospice primary diagnosis
- Progressive decline in Functional Assessment Staging (FAST) for dementia (from ≥7A on the FAST)
- Progression to dependence on assistance with additional activities of daily living (See Part II, Section 2)
- Progressive stage 3-4 pressure ulcers in spite of optimal care

# OTHER CONSIDERATIONS

- **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.
  - Chronic obstructive pulmonary disease
  - Congestive heart failure
  - Ischemic heart disease
  - Diabetes mellitus
  - Neurologic disease (CVA, ALS, MS, Parkinson's)
  - Renal failure
  - Liver Disease
  - Neoplasia
  - Acquired immune deficiency syndrome
  - Dementia

# PROGNOSIS-CANCER

- Part 1:
  - Disease with distant metastases at presentation.

  OR

  - Progression form an earlier stage of disease to metastatic disease with either
    - A continued decline in spite of therapy
    - Patient declines further disease directed therapy

  OR

  - Certain cancers with poor prognosis may be eligible without fulfilling the other criteria in this section:
    - Small cell lung cancer
    - Brain cancer
    - Pancreatic cancer

- Part 2:
  - Physiologic impairment of functional status as demonstrated by KPS or PPS <70%
  - Dependence on assistance of two or more activities of daily living (ADL)

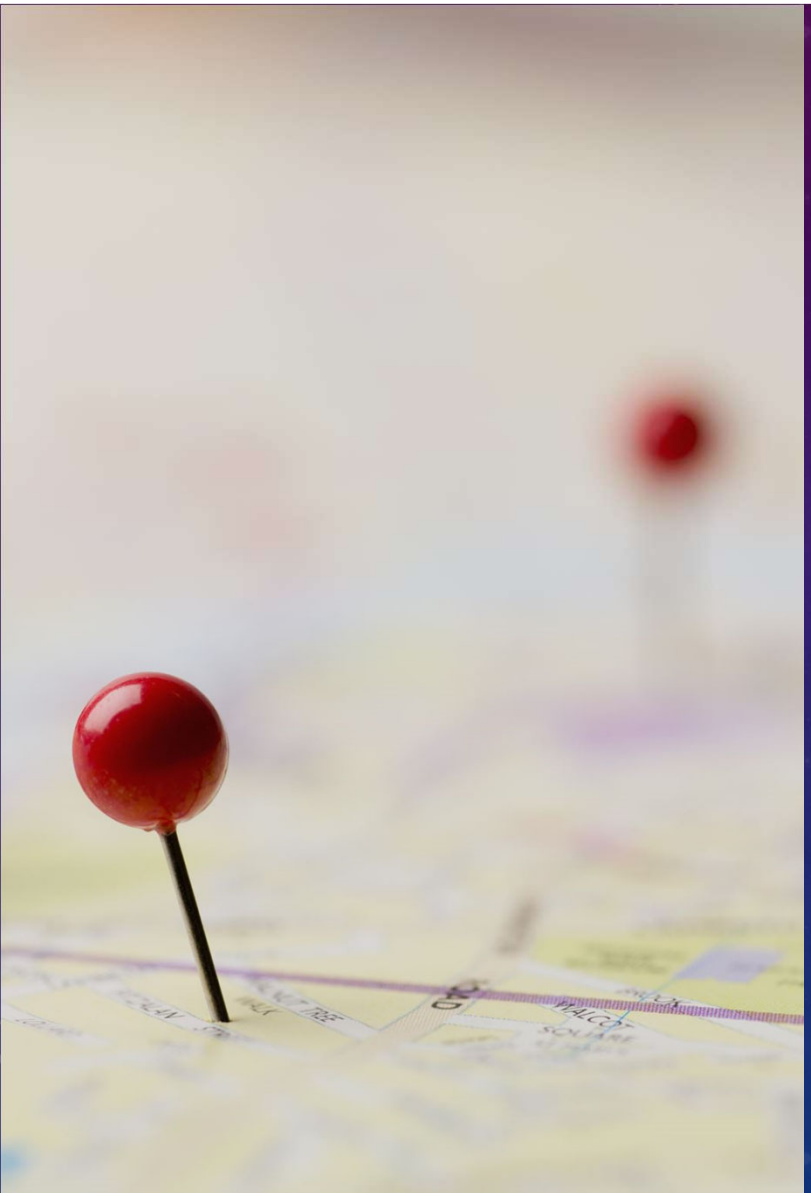
# CASE PRESENTATION

- Mr. Johnson is A 72 YO M with metastatic colon cancer and was recently admitted to your local hospital with sepsis. He does not have any further treatment options for his cancer. He was recently discharged and is seeing you today in clinic for follow up. His wife reports that Mr. Johnson has been spending more time sleeping, even prior to this admission, and now requires assistance bathing and dressing.

- Is Mr. Johnson eligible for hospice services?
- What additional questions might you have?

# INTRODUCING HOSPICE TO YOUR PATIENT

| Help | Present | Discuss | Suggest | Answer |
| --- | --- | --- | --- | --- |
| Help your patient identify important end of life goals.<br>•Spend more time at home instead of at the hospital, clinic, infusion center, etc.<br>•Increase time spent with family.<br>•Symptom control. | Present hospice as a means in which to meet these goals. | Discuss team-based approach of hospice care. | Suggest an informal meeting with local hospice agency. | Answer any remaining questions or concerns. |



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# Questions?