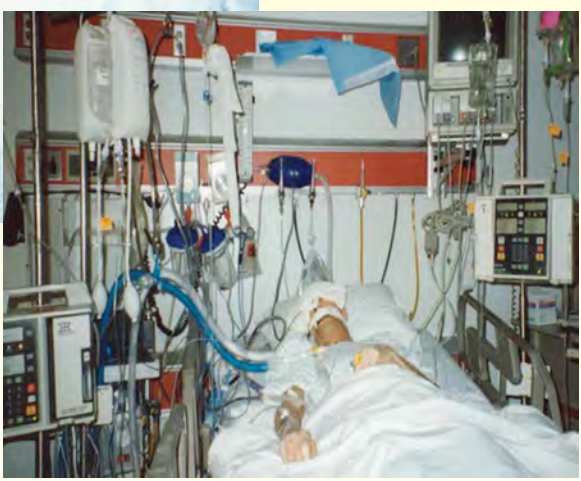

Do you
really know...
when it's time
for hospice?
HOSPICE
OF MARION COUNTY
Feel better. Live better.
THE JOINT COMMISSION
NATIONAL QUALITY APPROVAL
Deemed Status

*Would you be surprised*

if your patient died within 1 year?



*We can help you:*

identify end-of-life patients

*and*

offer care for those with chronic disease

# Table of Contents

# Patient & Family Benefits

**In choosing hospice**, patients and families make the decision to spend this precious time together at their own home or in a familiar and caring environment, such as one of our four hospice houses, an assisted living facility or a nursing home. With our sensitive supportive services and the physician's plan of care, patients and families feel a sense of relief as professionals walk with them through the phases of a terminal illness.

With us by your patient's side, you can expect:

- to remain the attending physician, if you wish
- excellent nursing care
- expert pain and symptom management
- social services available upon request
- regular patient status updates from our physician liaisons
- caring assistance from trained volunteers
- 24/7 call response, 365 days a year
- crisis care, if needed
- massage therapy, if requested
- acceptance of all eligible patients of all ages, including infants
- medications, medical equipment and supplies relative to the terminal illness, at no cost
- continuation of Medicare billing for office visits for your patients
- no co-payment or deductible for Medicare patients
- that no patient will be refused services due to inability to pay
- family bereavement support for up to 13 months after the death

# Predicting End-Of-Life Indicators

**The patient:**

- has ambiguous medical prognoses—those "living on thin ice" with multiple diagnoses
- demonstrates no clear transition when their illness goes from chronic to terminal
- has increasing office visits or hospitalizations
- is sick enough to die <1 year

# Classification of Chronic Diseases

| Non-fatal chronic diseases | Serious but eventually fatal chronic diseases | Nursing Home Residents |
|---|---|---|
| Arthritis | CHF | Frailty |
| Hearing loss | COPD | Fragility |
| Vision loss | Dementia | |
| | Kidney Failure | |
| | Cancer | |
| | CVA | |

# How Chronic Disease Leads to Death

- Gradual decline in health (i.e., 3 hospitalizations within 3 months)
- Single organ failure stresses other organ systems
- Loss in function with failure to return to previous levels of function
- Often sick with eventually fatal condition 3 years before death
- Caregiver stress escalates as patient worsens

# Dying is a Process

**It occurs over a 3-6 month timeframe**

- All patients behave the same—no matter the illness
- Go from eating to tasting to just looking at food
- Sleep-wake cycle reverses
- Decrease in functional ability
- Need more assistance with ADLs and IADLs

# Terminal Stage Signs (last 2-3 months)

- Beyond cure or rehab
- Progressive illness with limited life expectancy
- Anorexia/Cachexia Syndrome
- Progressive weakness
- Increasing debility/dependence
- Declining general condition
- Psychosocial/spiritual needs
- Time of family crisis

# Pre-active Stage Signs (last 2-3weeks)

- Little oral intake (<1 liter/24 hours)
- Incontinence (urine output <400cc/24 hrs)
- Increasing breathlessness, rising HR
- Reversal of sleep-wake cycle
- Delirium/restlessness/fluctuating LOC
- Spiritual events, i.e., "visits" from those already deceased/angels

# Imminent Death Syndrome (days-hours)

**Signs include:**

- Decreased responsiveness/consciousness
- Decreased intake food/water
- Decreased urine output
- Skin color and temperature decrease, cooling
- Livedo reticularis/mottling
- Decreased HR and BP (fluctuations)
- Swallowing dysfunction/death rattle
- Breathing changes/apnea
- Restlessness
- Gaze as if through you or through clouds

# Agonal Stage Signs (last 2-3 hours)

- Stupor/Coma
- Tachypnea (Cheyne-Stokes) agonal pattern
- Imperceptible radial pulses (last 4-6 hours)
- Tachycardia-Bradycardia-Asystole
- Pupils dilated, fixed (last 15-30 minutes)

# Death Event (last 2-3 moments)

- Spiritual experiences (moment of death)
- Bolt upright as if seeing; smiling
- Epiphora (final tear)
- Bright reflection
- Sense of calm (end of suffering/reunion)

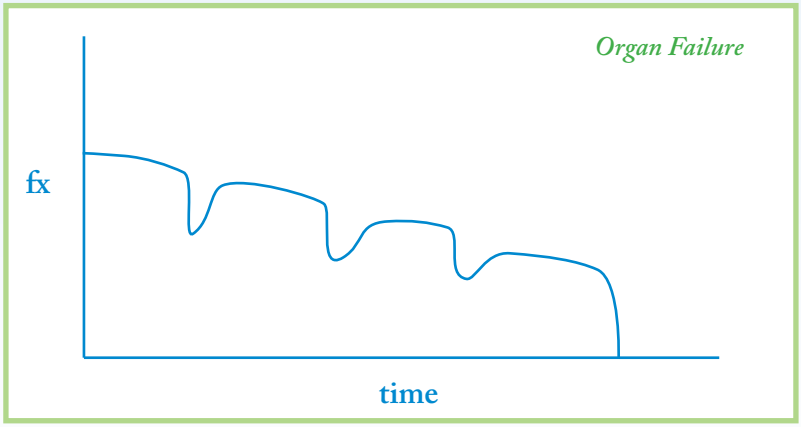
# Organ Failure

### Example: Liver Disease

- End-stage cirrhosis; not a candidate for transplant
- Prothrombin time >5 sec over control or INR >1.5 and serum albumin <2.5 g/dL
- At least one of the following:
  - Ascites despite diuretics and low sodium diet
  - Multiple paracenteses
  - Spontaneous bacterial peritonitis
  - Hepatorenal syndrome
  - Hepatic encephalopathy despite treatment
  - Recurrent variceal bleed

### Secondary Factors:

- Progressive malnutrition
- Muscle wasting
- Continued alcoholism
- Primary liver cancer
- Positive HBsAG



# What *hospice* can do to *help*:

- Pain and symptom management
- Paracentesis, as needed, to alleviate discomfort for liver disease
- Adjust medications based on symptom needs
- Assist with medication compliance
- Psychosocial and spiritual support to address issues such as guilt and anger
- Educate and comfort patient/family concerning disease progression
- Information about the signs of disease progression
- 24/7, 365 days a year
- Bereavement support for up to 13 months following a death

# Dying Trajectory

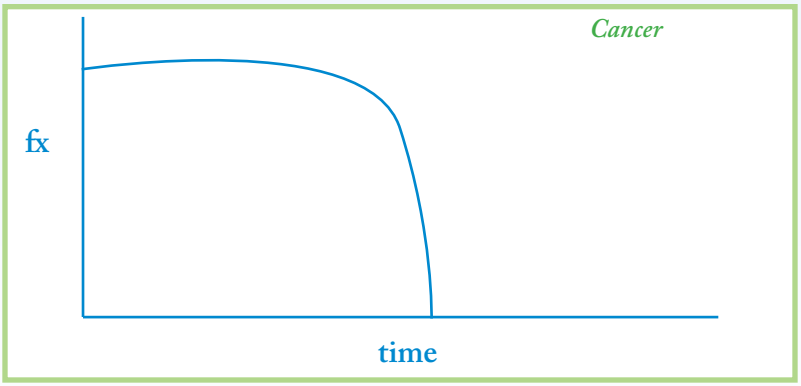
## Cancer

### 6-12 months before death:

- Palliative Performance Scale (measures function) <50%
- Need assist with ADLs or special care or assistance
- Mainly sitting or lying; unable to do any work
- Spends >50% of time in bed; limited self-care

### 30 days before death:

- Anorexia/cachexia
- Dysphagia
- Confusion
- Sun-downing
- Dementia
- Altered sleep/wake cycles
- Dyspnea
- Decline in general condition
- Increase in psychosocial/spiritual needs
- Hypercalcemia pericardial effusions
- Family crisis



# What *hospice* can do to *help*:

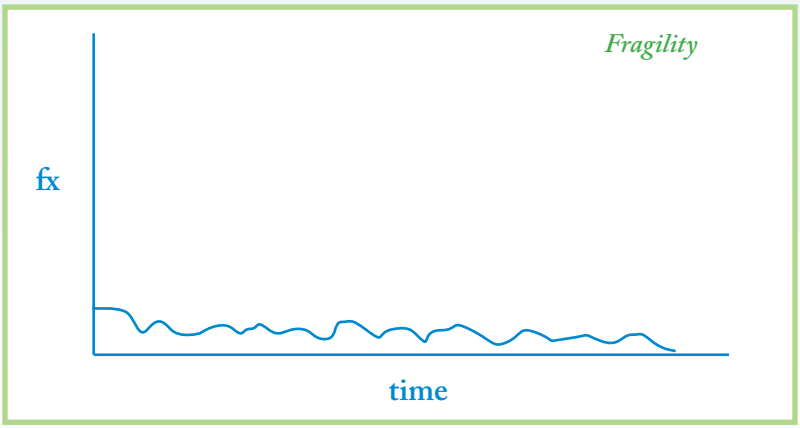
- Pain and symptom management
- Pain re-evaluation by physician house calls and nursing visits
- Other palliative treatments on a case-by-case basis
- Comforting support by staff for patient and family/caregivers
- Use of non-pharmacological therapies
- Assistance in making a plan of care for the entire family
- Education about expectations regarding disease progression
- Psychosocial and spiritual support for patient and family, including a children's specialist
- Available 24/7, 365 days a year
- Community resource assistance
- Bereavement support for up to 13 months following a death

# Dying Trajectory

## Fragility/Nursing Home

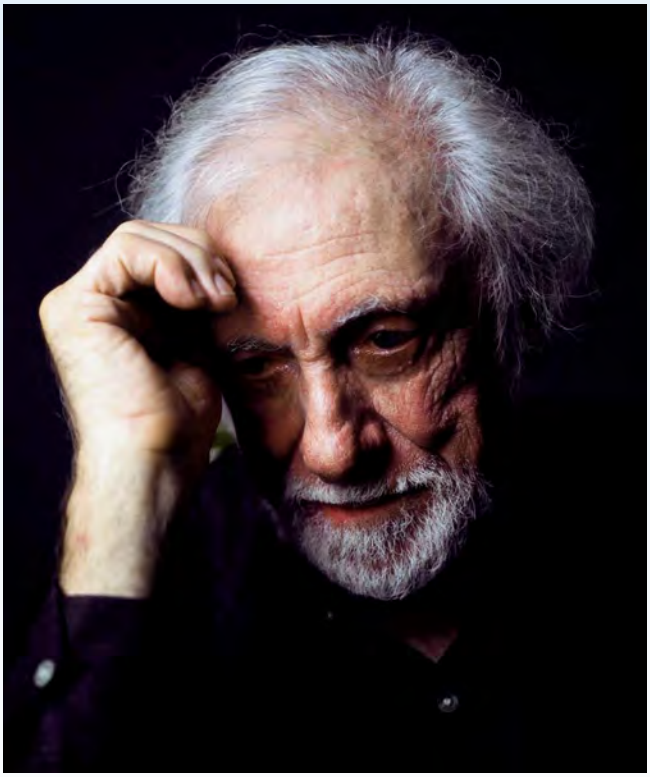
**Poor prognosis:**

- <2.5 albumin or drop in serum albumin >1.0 mg/dl
- New agitation without dementia
- New decubitus ulcer
- Decline in ADLs
- Weight loss
- >88 years
- Low BMI
- Difficulty swallowing
- Male
- CHF or dyspnea



# What *hospice* can do to *help*:

- Comfort care
- Pain and symptom management
- Explore reasons for unexplained weight loss
- Psychosocial and spiritual support for patient and family
- Coordination of care with the facility
- Dedicated Community Representative for facility
- Education for family as patient slowly declines
- Personal care (bathing, shaving, etc.)
- 24/7, 365 days a year
- Bereavement support for up to 13 months following a death

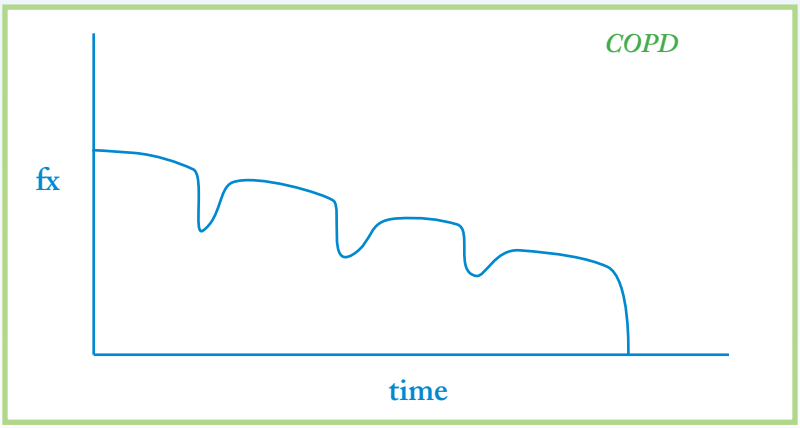


# Dying Trajectory

## Chronic Obstructive Pulmonary Disease

**Prognosis <1 year**

- <FEV1 <1.0 or FEV1 >40cc in 1 year
- Ambulatory patient with poor functional status
- Increase $CO_2$, CV morbidity
- Dependence on steroid/$O_2$
- Decrease in BMI, FEV1
- Dyspnea and exercise capacity
- Resting tachycardia >100 beats/minute



# What *hospice* can do to *help*:

- Symptom management for acute exacerbations
- Decrease physician office calls, 911 calls, hospitalizations
- Provide psychosocial support and medication for anxiety/ depression
- Cover medications, equipment, supplies related to symptom management of the terminal illness such as oxygen or inhalers
- Enhance quality of life
- Teaching regarding energy conservation, medication, equipment and non-pharmacological disease management
- Provide personal care for patient (bathing, shaving, etc.) which helps conserve patient's energy
- Psychosocial and spiritual support for patient and family
- 24/7, 365 days a year
- Bereavement support for up to 13 months following a death

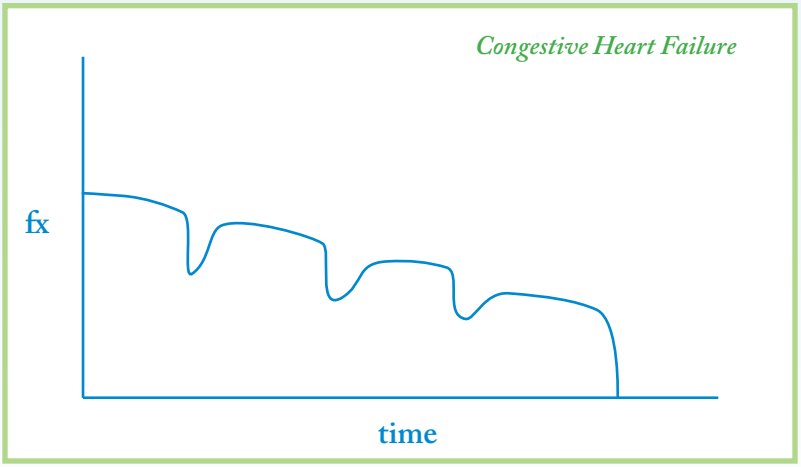
# Congestive Heart Failure

**Prognosis <1 year**

- Symptoms of recurrent heart failure or angina at rest
- Discomfort with any activity (New York Stage IV)
- Already optimally treated with diuretics and vasodilators (e.g. angiotensin-converting enzyme inhibitors)
- EF <20%
- Tachycardia
- Na <134
- BNP chronically elevated

**Secondary Factors:**

- Symptomatic arrhythmias
- History of cardiac arrest and CPR
- Unexplained syncope



# What *hospice* can do to *help*:

- Symptom management for acute exacerbations
- Decrease calls to the doctor and/or 911 calls
- Multiple trips to the ED or hospitalizations
- Psychosocial support and education
- Address issues of anxiety/depression
- Medications, equipment, supplies related to symptom management of the terminal diagnosis such as $O_2$ and nebulizers
- Enhancement of quality of life through Heartbeats program, which provides education on conserving energy, proper use of medication, equipment and non-pharmacological options
- Assistance with personal care, such as bathing, shaving, eating
- Psychosocial and spiritual support for patient and family
- 24/7, 365 days a year
- Bereavement support for up to 13 months following a death

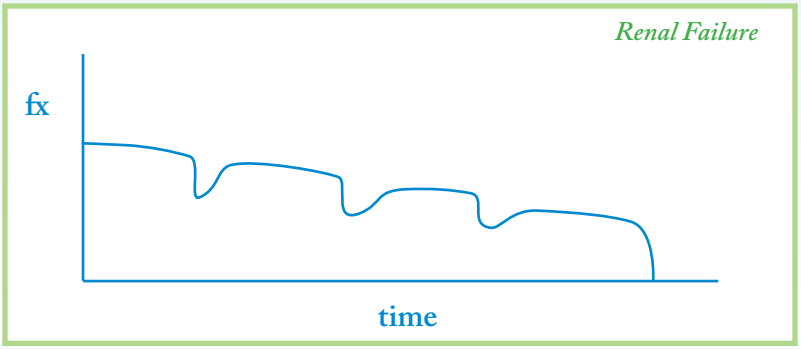
# End-Stage Renal Disease

### Prognosis <1 year

- Dialysis patients with increased time of recovery from dialysis, > 24 hour
- Creatinine clearance <10 cc/min (for diabetics <15 cc/min) AND serum creatinine > 8.0 mg/dL (for diabetics >6.0 mc/dL
- Uremia: nausea, pruritus, confusion or restlessness
- Oliguria: output <400 cc/24hrs
- Intractible hyperkalemia: serum K >7.0
- Uremic pericarditis
- Hepatorenal syndrome
- Intractable fluid overload

### Secondary Factors:

- Mechanical ventilation
- Malignancy of other organ system
- Chronic lung disease
- Advanced cardiac or liver disease
- Sepsis
- Decline in ADLs with increasing dependence on others for care



# What *hospice* can do to *help*:

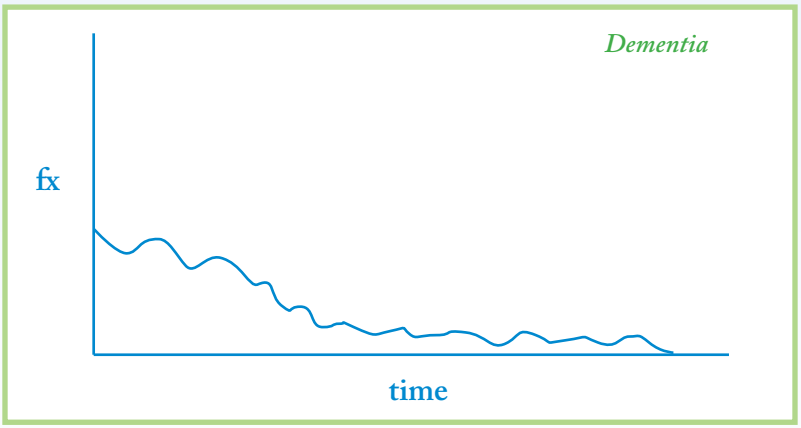
- Acute symptom management post-discontinuation of dialysis
- Assist with planning for end of life issues
- Offer life review and closure via social workers/chaplains
- Education about disease progression to prepare both the patient and family
- Psychosocial and spiritual support for patient/family
- 24/7, 365 days a year
- Bereavement support for up to 13 months following a death

# Dying Trajectory

## Dementia

**Prognosis <1 year (Stage 7)**

- Dependent all ADLs (Karnofksy <50%)
- Functional decline on FAST scale
- Urinary and fecal incontinence
- Decreased verbalization; <6 different words/day
- Decreased ability to ambulate
- Wasting >33% body weight
- Unable to maintain fluid/caloric intake to sustain life
- If feeding tube in place, weight loss >10% in 6 months or serum albumin <2.5 gm/dl
- Severe co-morbid condition within past 6 months
    - Aspiration pneumonia (i.e., 50% die in 6 months)
    - Pyelonephritis
    - Septicemia
    - Multiple, progressive stage 3-4 decubiti
    - Fever after antibiotics
- >83 years



# What *hospice* can do to *help*:

- Assist family in anticipating needs as patient declines
- Evaluate and manage non-verbal pain and other symptoms
- Treat infections
- Assist in teaching caregivers about nutrition and hydration
- Provide personal care for patient (bathing, shaving, eating)
- Facilitate placement to a facility if necessary
- Provide education about disease stages and progression
- Provide psychosocial and spiritual support for patient and family
- Reduce ED visits and hospitalizations
- 24/7, 365 days a year
- Bereavement support for up to 13 months following a death

# Dying Trajectory

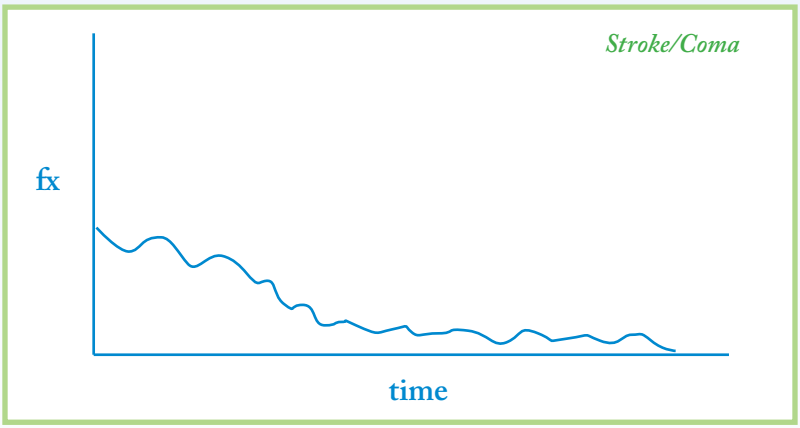
## Stroke/Coma

**Chronic phase after a cerebrovascular accident involves any one of the following:**

- Age >70 years
- Post-stroke dementia FAST score >7
- Assistance with ADLs
- Unable to speak >6 different words/day
- Occasional urinary or fecal incontinence
- Poor nutritional status
- Karnofsky <50%

**Secondary Factors:**

- Aspiration pneumonia
- UTI
- Sepsis
- Progressive refractory stage 3-4 decubiti
- Fever after antibiotics

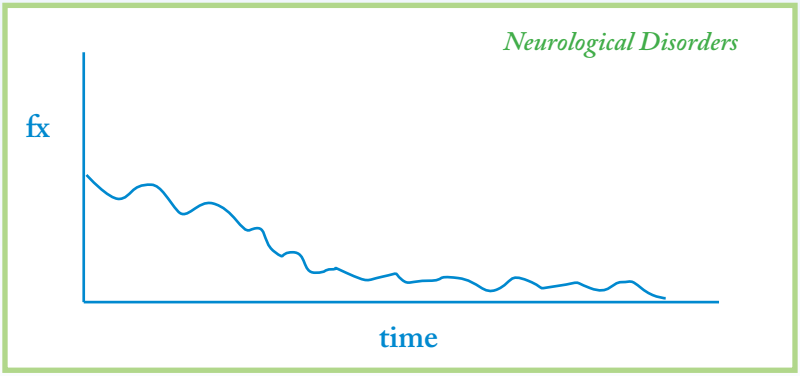


# What *hospice* can do to *help*:

- Ongoing assessment of medications to provide pain/symptom management
- Durable medical equipment delivered to patient specific to terminal disease
- Assist with facility placement
- Psychosocial and spiritual support for patient and family
- Education on disease progression to prepare family
- Physical, occupational or speech therapy as needed
- 24/7, 365 days a year
- Bereavement support for up to 13 months following a death

# Neurological Disorders (ALS, MS, Huntington's & Parkinson's disease)

- PPS score <70%
- Dependence on 2 or more ADLs (feeding, walking, bathing, etc.)
- Breathing capacity impairment
  - Vital capacity <30% of normal
  - Dyspnea at rest
  - Requires $O_2$ at rest
  - Declines artificial ventilation
- Critical nutritional impairment and rapid progression of disease
  - Assistance for ambulation, transfer
  - Speech unintelligible
  - Pureed diet; dehydration
  - Weight loss
- Final 12 months—life-threatening complications from:
  - Recurrent aspiration pneumonia
  - UTI
  - Stage 3-4 decubitis
  - Sepsis
  - Recurrent fever after antibiotic therapy



# What *hospice* can do to *help*:

- Ongoing assessment of disease progression
- Regulation of medications to palliate symptoms
- Durable medical equipment related to disease process delivered to patient
- Assist with placement in appropriate facility, if needed
- Psychosocial and spiritual support for patient and family
- Educate family about stages of disease
- Physical, occupational or speech therapy, as required
- 24/7, 365 days a year
- Bereavement support for up to 13 months following a death

# Decline in Function Scales

**The following scales** are measures to help the healthcare professional identify and rate a patient's decline.

**The Karnofsky Performance Status Scale** is one objective means of documenting a patient's clinical decline. Most patients with a Karnofsky scale of less than 50% are eligible for hospice care.

**The Palliative Performance Scale (PPS)** on the next page is an abbreviated version of the Palliative Performance Scale (PPSv2) version 2, modified for use in this guide only. Blank scaling forms are available from Hospice of Marion County Physician Liaisons by calling (352) 873-7400.

**The FAST chart** was specifically designed by NYU's Dr. Reisberg and his colleagues after observance of many patients with Alzheimer's.

## Karnofsky Performance Status

| Description of Function—Activities/Needs | Index |
|---|---|
| ☐ Normal, no complaints, no evidence of disease | 100% |
| ☐ Able to carry on normal activity, minor signs of symptoms of disease | 90% |
| ☐ Normal activity with effort, some signs of symptoms of disease | 80% |
| ☐ Cares for self, unable to carry on normal activity or to do active work | 70% |
| ☐ Requires occasional assistance but is able to care for most of own needs | 60% |
| ☐ Requires considerable assistance and frequent medical care | 50% |
| **<50% = Hospice Referral** | |
| ☐ Disabled, requires special care and assistance | 40% |
| ☐ Severely disabled, hospitalization indicated although death not imminent | 30% |
| ☐ Very sick, hospitalization necessary, active supportive treatment necessary | 20% |
| ☐ Moribund, fatal processes progressing rapidly | 10% |
| ☐ Dead | 0% |

## Palliative Performance Scale

| Activity & Evidence of Disease | Ambulation | PPS Level |
|---|---|---|
| ☐ Normal activity & work; No evidence of disease | Full | 100% |
| ☐ Normal activity & work; Some evidence of disease | Full | 90% |
| ☐ Normal activity with effort; Some evidence of disease | Full | 80% |
| ☐ Unable to do normal job/work; Significant disease | Reduced | 70% |
| ☐ Unable to do hobby/housework; Significant disease | Reduced | 60% |
| ☐ Unable to do any work; Extensive disease | Mainly sit/lie | 50% |
| ☐ Unable to do most activity; Extensive disease | Mainly in bed | 40% |
| ☐ Unable to do any activity; Extensive disease; Reduced oral intake | Totally bed bound | 30% |
| ☐ Unable to do any activity; Extensive disease; Minimal oral intake | Totally bed bound | 20% |
| ☐ Unable to do any activity; Extensive disease; Mouth Care Only | Totally bed bound | 10% |



## Functional Assessment Staging (FAST) scale assesses the decline of patients with Alzheimer's disease.

| FAST Scale Stage | Characteristics |
|---|---|
| 1... normal adult | No functional decline. |
| 2... normal older adult | Personal awareness of some functional decline. |
| 3... early Alzheimer's disease | Noticeable deficits in demanding job situations. |
| 4... mild Alzheimer's | Requires assistance in complicated tasks such as handling finances, planning parties, etc. |
| 5... moderate Alzheimer's | Requires assistance in choosing proper attire. |
| 6... moderately severe Alzheimer's | Requires assistance dressing, bathing, and toileting. Experiences urinary and fecal incontinence. |
| 7... severe Alzheimer's | Speech ability declines to about a half-dozen intelligible words. Progressive loss of abilities to walk, sit up, smile, and hold head up. |

Developed by NYU Medical Center's Aging and Dementia Research Center,
Barry Reisberg, MD

# Why Discuss End of Life?

- Patients can make informed decisions that are congruent with their preferences and more consistent with their medical condition
- Make practical decisions about living arrangements and financial matters
- Seek spiritual support
- Provide opportunity for advance care planning
- Achieve reconciliation and closure and say goodbye to loved ones

# Prognostication Success

**Several studies show physicians:**

- Have a tendency to overestimate life expectancy (by a factor of 5.3)
- Are often reluctant to make prognoses
- Consciously communicate overestimation to patients/families

**When** is the time to discuss prognosis?

**Now** would you be surprised if the patient were still alive in 6 months or a year?

If the answer is **yes**, it's time.

# Patients And Families Want To Know

- Models using APACHE scores
- Low EF with CHF, FEV1 ~ 50% die in 1 year
- Cancer patients with PPS <50% die <6 months

# The Difference Between Home Care and Hospice?

| Service | Home Health | Hospice of Marion County |
|---|---|---|
| Excellent Nursing Care | Yes | Yes |
| Home Health Aides Available | Yes | Yes |
| Medicare/Medicaid Certified | Yes | Yes |
| 24-Hour On-Call Nursing | Yes | Yes |
| Social Service On-Call 24 Hours, As Needed | Yes | Yes |
| Deductibles and Co-Payments Waived | Varies | Yes |
| Volunteers for Special Needs and Respite | No | Yes |
| Medications, Cost Free, if related to terminal illness | No | Yes |
| Cost-Free Supplies | No | Yes |
| Cost-Free Medical Equipment | No | Yes |
| Continue to manage when in Hospital | No | Yes |
| Nursing Home Program | No | Yes |
| Program available to Dying Children | No | Yes |
| Spiritual Care Available | No | Yes |
| Resident Facility for Terminal Patients | No | Yes |
| Family Bereavement Support for 13 months after Death | No | Yes |
| *Eliminates Home-Bound Requirement | No | Yes |

*Regulatory guidelines mandate that home health patients may not leave their homes, except for MD visits, medical tests, dental appointments, ophthalmic appointments and occasional church visits. Hospice patients are allowed and encouraged to participate in as many of their normal activities as possible.

**If you have questions about eligibility, just call the Admissions Department at 352-873-7415.**

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**Developed by**

**Segismundo Pares, MD**

**Bonnie Parsons, RN, MSN, GNP-BC**

# Just for Physicians

## Our goal is to be a partner in the care of your patients.

To that end, our Physician Liaisons who regularly visit your office are now empowered to provide you with updated Patient Status Reports, hand-delivered to your office. Please call on them if you have concerns, questions or need information.

This is their role in closing the loop once your patient is admitted to hospice care, and they look forward to serving you.

## Visit our Physician Reference Web Page

**www.hospiceofmarion.com/physicians.html**

or click the Physician Reference left-hand tab on the Home Page.

You'll find downloadable forms on:

- The Top 10 Terminal Diagnoses Guidelines
- Functional Scales: Palliative Performance, Karnofsky, Pain Assessment (VAS—Visual Analog Scale) and FAST
- Hospice Certification Form
- Medicare Billing for Physicians with Patients on Hospice
- Physician Payment Guide

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SINCE 1983

**Hospice of Marion County**
3231 SW 34th Ave.
Ocala, FL 34474
Main number: 352-873-7400
Admissions: 352-873-7415
**www.hospiceofmarion.com**