Honoring Preferences: Goals of Care Conversations, Palliative Approaches and Assessing Hospice Eligibility

Elizabeth Balsam Hart, MD

Medical Director

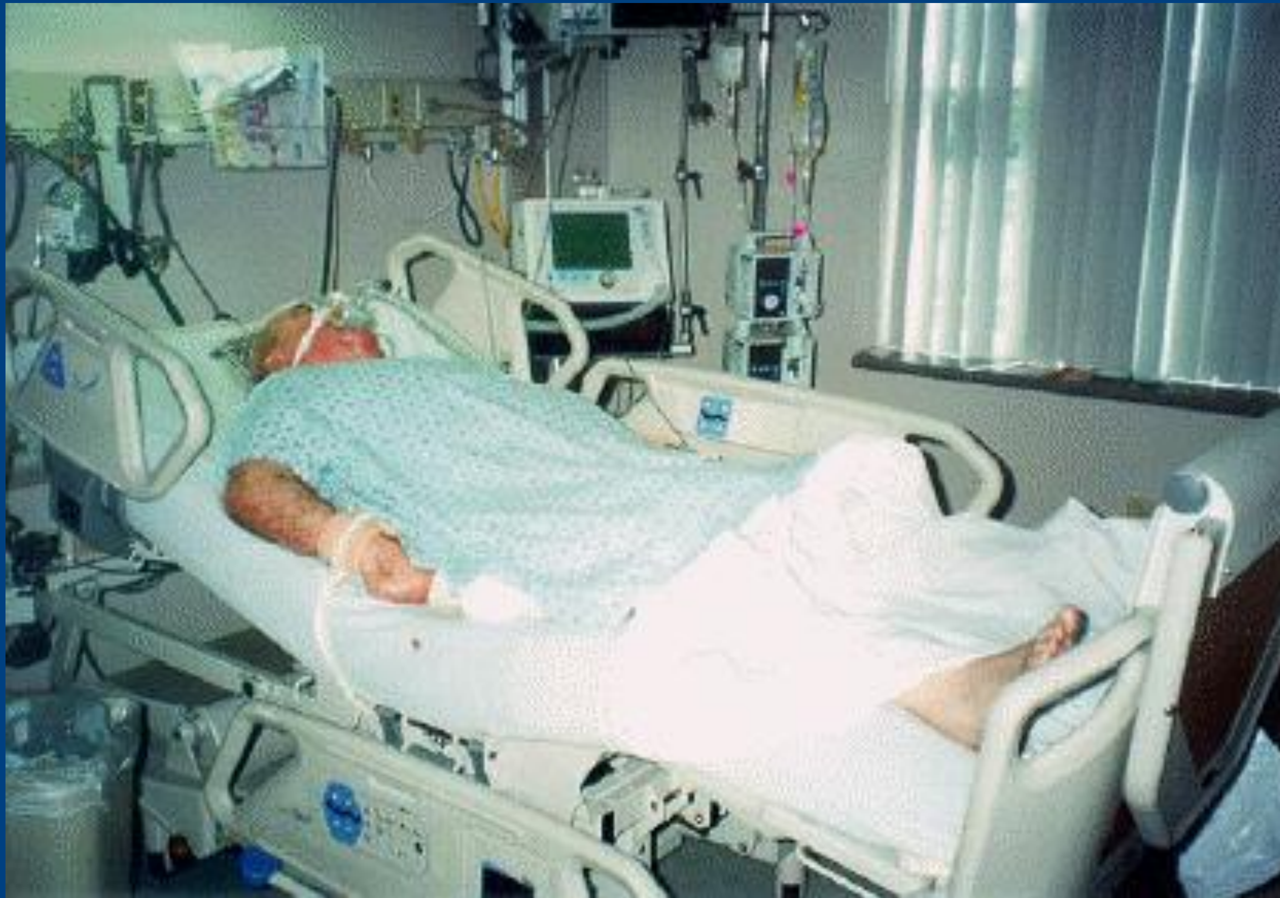
MaineGeneral Hospice

MaineGeneral Community Care

- Elizabeth Hart DOES NOT have an interest in selling a technology, program, product, and/or service to CME/CE professionals.
- Elizabeth Hart has nothing to disclose with regard to commercial relationships.
- The content of this presentation does not relate to any product of a commercial interest. Therefore, there are no relevant financial relationships to disclose.

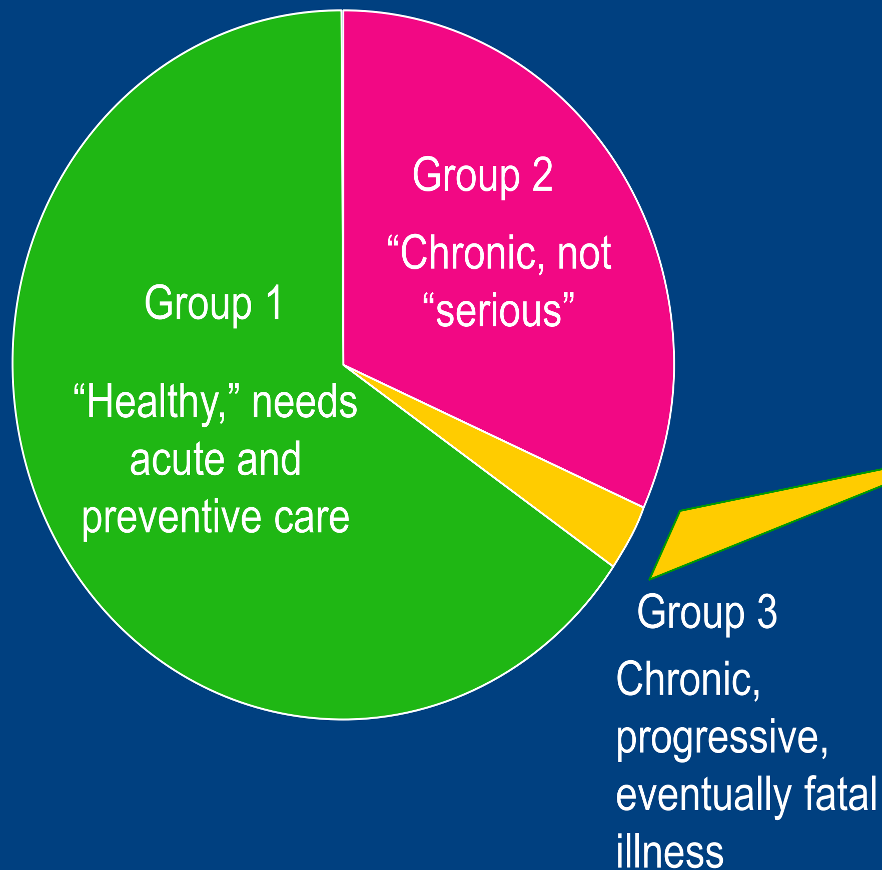
"How people die remains in the memories of those who live on."

Dame Cicely Saunders

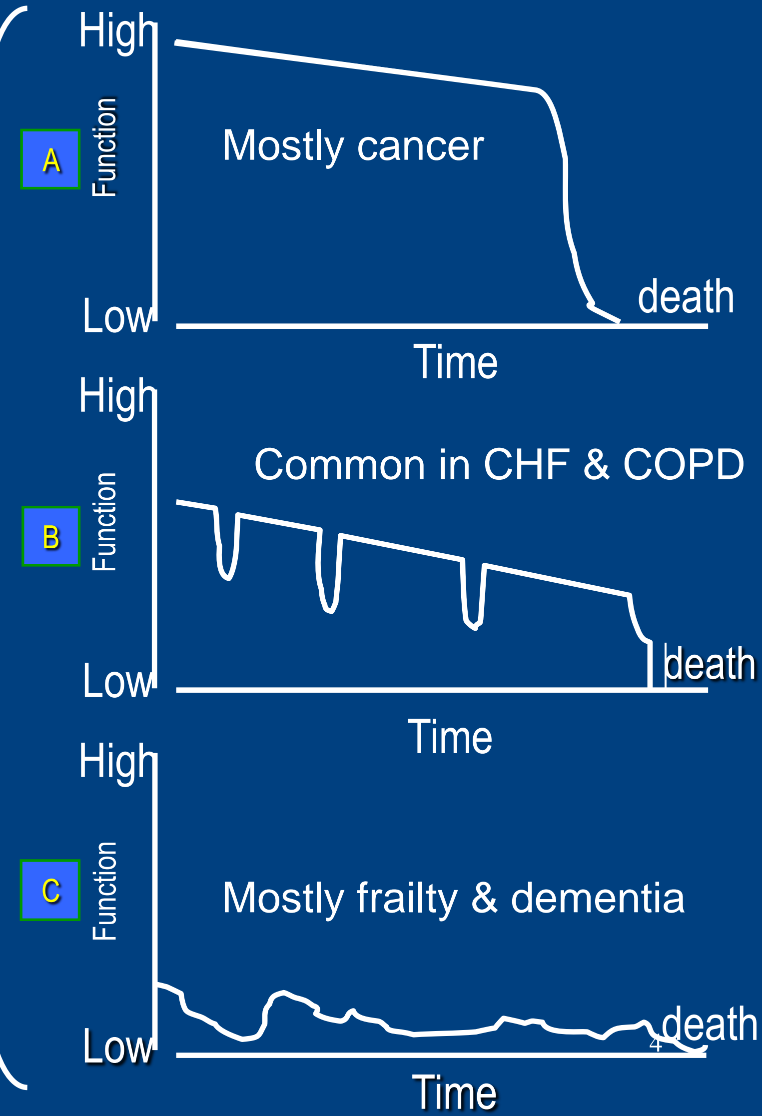


Divisions by Health Status in the Population and Trajectories of Eventually Fatal Chronic Illnesses

Divisions in the Population



Major Trajectories near Death



Adapted from Lynn and Adamson, 2003, **Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age.** RAND White Paper. As Cited in *BMJ 2005;330:1007*

The Surprise Question

"Would you be surprised if __________with advanced _______ died in the next year?"

Establish Realistic, Attainable Goals

- Help facilitate an understanding of the scope of illness and likely progression
- Identify relevant values and goals
- Define ***"acceptable"*** and ***"unacceptable"*** quality of life
- Encourage consideration of goals of treatment in context of non-illness related priorities. "What matters most?"

Questions to Help Establish Goals of Care

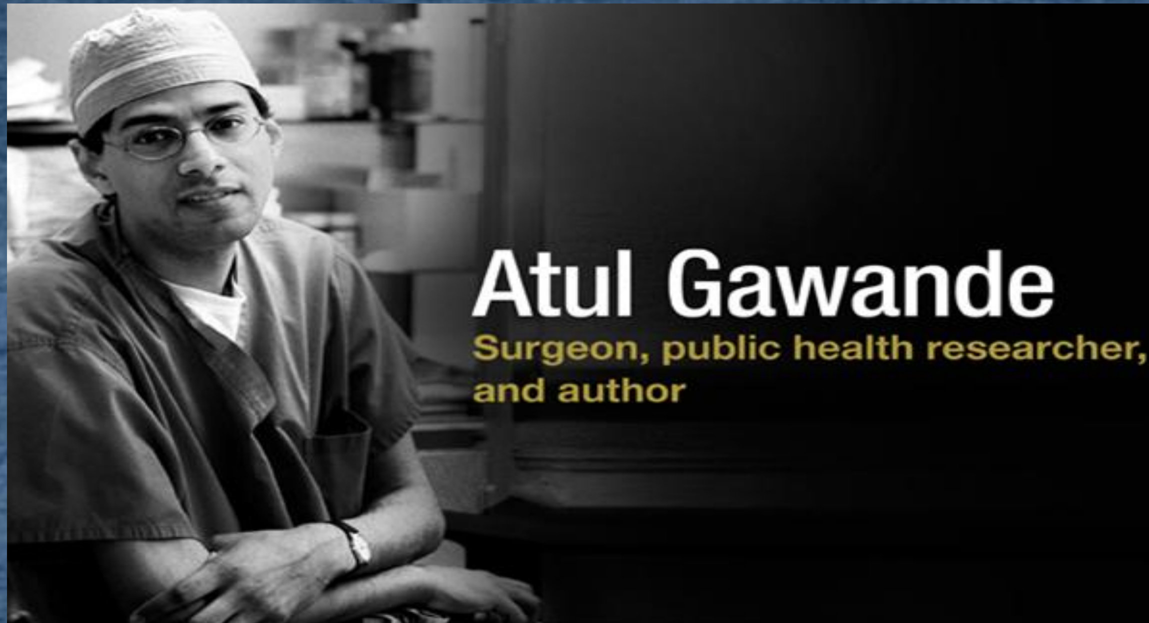
- “What concerns you most about your illness?”
- “As you think about your illness, what is the best that might happen?”
- “What is the worst?”
- “What are your greatest fears?”
- “What are your hopes for the future?”

(Quill TE. *JAMA*; 284:2502-7; Lo et al. *Ann Intern Med;* 1999: 744-9)

"To code or not to code?"
Maybe that's not the most important question
…Instead…

- "How do you want to live until you die?"
- Start by asking "What do you understand about the illness and its expected course?"
- "What is important to you in the time you have left?" (or surrogate/POA might imagine person's response based on previously known values)

- https://www.youtube.com/watch?feature=player_detailpage&v=45b2QZxDd_o



Hard Choices for Loving People

- An outstanding resource written for patients and their families/caregivers
- Not in complicated healthcare language
- Written by Hank Dunn, a practical and reflective nursing home and hospice chaplain
- Not based on one faith or set of values
- Available at www.hardchoices.com

Advance Care Directives: Recommendations

For all adults

- Designate HealthCare Power of Attorney (Agent)
  - POA who understands goals is most "responsive" model
  - Prepare POA for "in the moment decision making" as per Sudore and Fried*
- "Living will"

For those who are seriously ill or near the end of life

- Non-hospital "Do Not Resuscitate" (DNR) order
- Physician Orders for Life Sustaining Treatment (POLST)
- POLST is not a tool to appoint POA, only identifies who it is

*Ann Intern Med. 2010;153:256-261

Redefining the "Planning" in Advance Care Planning

Sudore and Fried, Ann Intern Med. 2010;153:256-261

"No form or checkbox will ever eliminate the uncertainty and the complexity of the human condition."

-Rebecca Sudore-
California Coalition for Compassionate Care Conf. February 2012

Redefining Advance Care Planning

(http://coalitionccc.org/documents/Rebecca_Sudore_Presentation.pdf)

- Prepare patients and surrogates to:

-work with clinicians to make the best possible “in-the-moment” decisions

-consider complex decisions based on clinical context, evolving goals & needs

- Step 1: Choose a surrogate
- Step 2: Clarify values over time
- Step 3: Establish leeway in decision making

Substituted Judgment

- Important to help POAs/ Caregivers/ Family to understand this principle - not what you or I think is best - but what patient would have wanted.
- If ______could look down on their situation right now, what would they tell you about what is important to them ?
- Several studies show that neither healthcare providers nor surrogates are accurate in knowing or predicting patient’s preferences
- http://www.amda.com/governance/whitepapers/surrogate/surrogate.pdf

Capacity for Medical Decision Making
(Capacity is Task Specific)

- Can the patient demonstrate the ability to communicate a choice? (not necessarily verbally)
- Does the patient understand his or her medical condition and the relevant facts? (risks, benefits of proposed intervention and alternatives)
- Does the patient understand the available options and the consequences of his or her decision?
- Is the decision based on reasoning consistent with the patient's values/ preferences?

http://www2.med.psu.edu/humanities/files/2013/07/Assessing-Decision-Making-Capacity.pdf

Conversations: Essential Steps

1. Prepare for the discussion
2. Begin with assessing patient and family understanding
3. Provide any new information about the patient's condition and values from medical team perspective
4. Try to reconcile differences in terms of prognosis, goals, hopes and expectations
5. Focus on achieving overall goals, not just on specific interventions
6. If completing a POLST, use POLST to guide choices and finalize patient/family wishes
7. Document conversation. Who, when where? Values decisions based on.
8. Review and revise periodically (change in care-setting, condition or goals)

Creating an Environment in which it is Comfortable to Have Difficult Conversations

- Takes time
- Non-judgmental approach
- Reflective process to consider what gives life meaning
- Respecting difference
- Honesty
- Acknowledgement of feelings of grief and guilt even when appropriately following patient's wishes

Additional questions we might reflect upon (Or might consider loved one’s response)

- “Has anything happened in your past that shaped your feelings about medical treatment?”
- “What frightens you most about medical treatment?”
- “Under what circumstances would you want goals to switch from attempting to prolong life to focusing on comfort?”
- “Ask yourself…what will most help me to live well at this point in my life?’

"Making Choices" Advance Care Planning Guide;
Gundersen Lutheran Medical Foundation

Some questions to consider about a proposed intervention?

- Is the goal to provide comfort?
- Is the goal to extend life?
- Is this life-enhancing or life-prolonging?
- Are we prolonging the dying process?
- Might ask…"If treatment doesn't go as hoped, what would be most important to you?"
- How does the intervention impact what gives life meaning at this time in the illness - connections, joys, spirituality, relationships?

For specific interventions, encourage consideration of benefits and burdens

- Will the intervention:

  -Help me live longer?

  -Improve my quality of life?

  -Enable me to do be more functional?

  -Lessen my suffering?
- What are the burdens and side effects of proposed treatments?

Palliative Considerations about Dietary Modifications

- Risks of dietary modifications in advanced illness, especially in long-term care.
- Risk of less enjoyment of food, weight loss on restricted diet, dehydration due to decreased fluid intake with thickeners vs potential risk of aspiration
- May aspirate on own secretions
- Consider Frazier Water Protocol
  - Patients on thickened liquids allowed water between meals

Palliative Considerations about Dietary Modifications

- Risks of dietary modifications in advanced illness, especially in long-term care.
- Risk of less enjoyment of food, weight loss on restricted diet, dehydration due to decreased fluid intake with thickeners vs potential risk of aspiration
- May aspirate on own secretions
- Gawande story
- Consider Frazier Water Protocol
  - Patients on thickened liquids allowed water between meals

Some Elements of Frazier Water Protocol

(excerpted from https://www.temple.edu/.../PMR_presentation_skills_ Free_Water_Protocol. ppt)

- Pills not given with water. Given in applesauce/pudding
- Need to be able to swallow without excessive cough or discomfort
- Alert and able to remain upright
- Aspiration of oropharyngeal pathogens frequent cause of nursing home acquired pneumonia. Poor oral health increases risk of developing aspiration pneumonia
- Aspirating oral bacteria likely greater risk than aspirating water… so key is excellent mouth care

Counseling Patients and Families Concerning Do Not Hospitalize Orders

- We must weigh burdens as well as potential benefits of hospitalization for acute declines

- Possible reasons for hospitalization:
  - Symptom management
  - Treatment of acute injury (e.g. hip fracture)
  - Aggressive evaluation and treatment
  - Patient and family preference and medical indication

Discussing Place of Care at Late Stage Explain Burdens of Hospitalization

- Anxiety or confusion getting used to new surroundings, caregivers and routines (Fear and loneliness as medical harms)
- Increased risk of infections and delirium
- Increased possibility of restraints/sedation
- Increased possibility of aggressive testing and treatment ***- Medical Cascade-***
- Tests may be especially burdensome if would not want treatment for what they may reveal (Anemia example)

Discuss Options for Care in Home or Nursing Home Setting

- If care consistent with goals could be provided at home, or in the nursing home, what are goals of hospitalization?
- Home health, hospice and nursing homes often can provide care that meets goals; including pain control, symptom relief, and in some facilities IV antibiotics etc.
- Patients often want to avoid rehospitalization, just as we want to minimize this risk.

""""”Hard Choices for Loving People"
Hank Dunn

Examples of clear and simple language to describe interventions such as CPR

- CPR is a group of treatments that attempt to reverse death when someone’s heart stops or breathing stops

- Basic CPR includes “applying force to the chest with the hands, compressing the heart, and pumping air into the person’s mouth filling the lungs with air”

Examples of clear and simple language to describe interventions such as CPR

- More advanced CPR includes:
  - administering intravenous medications
  - insertion of tube down the throat into the windpipe to pump air in and out of the lungs when the person is unable to breathe on his/her own
  - often remain on a machine (ventilator) after
  - electrical stimulation of the heart with paddles (shocking or defibrillating)

"Hard Choices”
and Oregon POLST brochure

Use simple language to describe when CPR is most likely to be effective

- Developed originally for "sudden death" such as drowning, electrical shock, sudden heart attack in healthy person
- Greatest chance of survival if:
  - Certain abnormal rhythms (example - ventricular fibrillation)
  - Respiratory arrest only
  - Generally healthy without other illness

"Hard Choices for Loving People,"
Hank Dunn

In Advanced Illness Resuscitation is Unlikely to be Successful

- 10-17% of people of all ages with attempted in-hospital resuscitation survive to discharge, most with impaired function (=avg of approximately 1 out of 7)
- Outcomes much worse for out-of-hospital, unwitnessed or prolonged arrest, & chronic illness
- Especially poor in dementia, cancer, renal failure, sepsis and multi-organ failure
- Chronic illness, more than age, determines prognosis (<5% survival)
- CPR effective in < 3% of frail nursing home residents

https://www.capc.org/fast-facts/179-cpr-survival-hospital-setting
EPEC Project RWJ Foundation, 1999
"POLST at Work" video; Oregon POLST Program 2012
www.hardchoices.com

Explain Risks of CPR

- Death despite attempted resuscitation
- Prolonged stay in ICU with morbidity for patient and family
- Survival with decreased neurologic function or other organ compromise
- Fractured ribs, especially if frail
- Ruptured or punctured spleen, liver or lung
- Reduced possibility of peaceful death with dignity in calm setting

Discuss Benefits and Burdens of Artificial Nutrition at the End-of-Life Using Straightforward language

- Weight loss and difficulty swallowing are expected course of many terminal illnesses (especially common in dementia)
- We associate feeding with nurturing and caring; food is sign of love and life
- Artificial nutrition offers different benefit when need for temporary nutrition such as after surgery, or process primarily affecting swallowing

Discuss Benefits and Burdens of Artificial Nutrition at the End-of-Life Particular concerns in cognitively impaired

- Research shows artificial nutrition does not offer benefit in dementia
- Survival not prolonged and functional status not improved with tube “feeding” in dementia
- May decrease quality of life
- Less one-on-one nurturing than with hand feeding in dementia
- Not the same as eating, with enjoyment of food’s textures, tastes and smells and social contact
- Often requires restraints

Discuss Benefits and Burdens of Artificial Nutrition at the End-of-Life

- Tube “feeding” may increase (rather than decrease) risk of aspiration pneumonia, especially in patients with certain risk factors including: impaired level of consciousness, neurological and cognitive deficits, mechanical ventilation, poor oral hygiene/oral health

-Practical Gastroenterology, April 2003

- Risk of local and systemic infection, diarrhea, immobility, restraints

Discuss Benefits and Burdens of Artificial Fluids at the End-of-Life

- Dying process usually includes stopping drinking, sometimes days before death
- Dehydration is a common pathway of many terminal illnesses
- Other than dry mouth, generally not experienced by dying people as would be for a healthy person on a hot day
- Dry mouth may be relieved by mouth care, swabbing and ice chips, and may not be relieved by artificial hydration

Discuss Benefits and Burdens of Artificial Fluids at the End-of-Life

- Benefits of allowing natural decrease in fluid intake in final days of life include:
  - Less urination and less skin breakdown
  - Natural release of pain-relieving chemicals (called endorphins or natural opiates), which is suppressed if give artificial fluids
  - Less swelling
  - Less fluid in lungs and easier breathing
  - Usually a gentle, gradual process of dying

Address the Unspoken Concerns in End-of-Life Care

- “My mother will starve to death without food or nutrition.”
- “My husband will die of thirst.”
- Opportunity to explain that their loved one is dying of the underlying illness and that stopping eating and drinking is a natural part of the dying process

Discuss Antibiotics for Comfort, vs Attempt to Cure Reversible Illness, vs Other Ways of Relieving Symptoms

- May use antibiotics to attempt to reverse infections such as pneumonia, UTI, cellulitis
- May use only for comfort to relieve symptoms
- May specify route
- Not treating infection may progress to “gentle” death after long illness; pneumonia as “old man’s friend”.
- If consistent with goals, may specify no antibiotics

Consider Hospice to Achieve Patient Goals

Hospice may be an option for patients with advanced illness whose goals include:

- Maximizing function through frequent attentive symptom assessment and management, facilitated by a team with expertise in palliative approaches
- Living as fully as possible, with support from an interdisciplinary team
- Minimizing frequency of hospitalizations or avoiding hospitalization entirely

Certified Hospice Care

Hospice Eligibility

- Physician certification (by attending physician and hospice medical director) of terminal diagnosis with prognosis likely to be <6months, if the illness progresses with usual course (may be <12 mos. for some private insurances)
- Seeking comfort/palliative care (though some private insurances may cover ongoing concurrent therapies)
- Patient election of hospice benefit

Hospice care is provided by a specially trained team

- MaineGeneral Hospice team includes:
  - Registered Nurses
  - Social Workers
  - Home Health Aides
  - Chaplain
  - Medical Director
  - Hospice Volunteers
    - Hospice Volunteers of Somerset County
    - Hospice Volunteers of Kennebec Valley
    - Hospice Volunteers of Waterville Area
  - Consulting Pharmacist
    - Kennebec Pharmacy and Home Care
  - Additional services
    - PT/OT/ST
    - Dietary counseling
    - Massage, art therapies and music practitioner visits
    - Pet Therapy

Hospice care covers:

- Medications and services “necessary for the palliation and management of the terminal illness and related conditions” (including medical equipment and supplies)
- General Inpatient (GIP) admissions
- Respite care
- Additional MaineGeneral Hospice Programs:

  “Intensive Comfort Care” at EOL

  “Tender Care” Volunteer Team

  Dementia Care Program

Respite

- Respite: *An interval of rest or relief*
  - Scheduled admission at a contracted facility
  - May access up to 5 consecutive days on an occasional basis
  - Prior authorization: Attending Physician, Hospice team
  - Intent of respite admission

Late Hospice Referrals are Common

- National Hospice Data in 2013*

34.5% of hospice patients died (or discharged) within 7 days of admission to hospice

48.8% received services for < 14 days

Median Length of Stay (LOS) = 18.5 days

*National Hospice and Palliative Care Organization:
Facts and Figures: Hospice Care in America, 2014 ed.
http://www.nhpco.org/sites/default/files/public/Statistics_Research/2014_Facts_Figures.pdf

Benefits of Earlier Hospice Referrals

- Time to build trusting relationships with patients and families
- Better symptom management
- Reduced caregiver stress
- Improved social and spiritual support
- Avoid rehospitalization if that is pt's goal, (though hospice patients can be hospitalized if indicated)
- More cost effective hospice care
- Bereavement often less complicated for families when have built relationship with hospice team over time

Hospice Guidelines are *guidelines*: Main eligibility determinants are clinical assessment, judgment and documentation

- General Decline
  - Increased dependence in ADL's : bathing, eating, dressing, walking, toileting, transferring
  - Multiple co-morbidities
  - Progressive weight loss: 10% in last 6 months Progressive stage 3-4 pressure ulcers
  - Increasing need for medical care: ED visits, hospitalization, physician visits
  - Recurrent or intractable serious infections
  - Progression of disease documented by worsening clinical status (symptoms, signs, labs)

Cancer

- Metastatic disease
- Progression to metastatic disease
- Functional decline and comorbidities are relevant to assessment of overall clinical status

End-Stage Heart Disease

- Dyspnea or angina at rest, progressing despite maximal medical management
- Any physical activity causes pain or dyspnea
- Treatment resistant arrhythmias
- History of cardiac arrest or resuscitation, brain embolism of cardiac origin, active HIV
- Known ejection fraction $\leq$20% (not required if not available)

End-Stage Pulmonary Disease

Progression of severe chronic lung disease including:

- Disabling dyspnea at rest, refractory to treatment
- Bed to chair existence
- Recurrent pulmonary infection
- Increasing ED visits or hospitalizations
- Resting tachycardia >100/minute
- Cor pulmonale / right heart failure
- Weight loss > 10% of body weight in last 6 months
- O_2 sat <88% (at rest, on room air)
- pCO_2 > 50mm Hg

Dementia due to Alzheimer's Disease and Related Disorders

The presence of the following characteristics:

- Dependence for all ADL's, including ambulation
- No consistently meaningful communication
- Urinary and fecal incontinence

One of the following or a another significant co-morbidity or secondary condition within last year:

- Fever recurrent after antibiotics
- Pressure ulcers, stages 3-4
- Infections including: sepsis, pneumonia, pyelonephritis
- Malnutrition with 10% weight loss in past 6 mos
- Serum albumin <2.5gm/ml

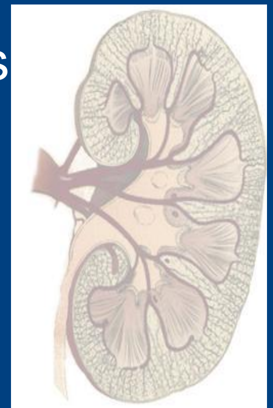
Stroke and Coma

- Stroke:
  - Inability to maintain hydration and nutrition with one of the following:
  - Weight loss, albumin < 2.5, aspiration, dysphagia
- Coma: Persistent vegetative state 3 days or longer
- Supportive documentation: progressive decline within last 12 months, with documentation of medical complications such as:
  - Aspiration pneumonia
  - Pyelonephritis
  - Stage 3-4 pressure ulcers
  - Fever despite antibiotics

End-Stage Renal Disease

Patient not seeking a transplant or ongoing dialysis, and has one of the following:

- Creatinine clearance
  - < 10 cc/min (<15 cc/min. in diabetes)
  - < 15cc/min (< 20 cc/min in diabetes) with comorbidity of CHF.
- Serum creatinine > 8 mg/dl (> 6 mg/dl in diabetes)
- Estimated glomerular filtration rate (GFR) <10 ml/min.
- Signs and symptoms of kidney failure:
  - Uremia, nausea, vomiting, confusion, pruritis
  - Oliguria (<400ml/24hr)
  - Hyperkalemia (>7.0)
  - Intractable fluid overload
  - Not-responsive to medical management



Liver Disease

INR >1.5 and serum albumin < 2.5 gm/dl

The presence of at least one of the following:

- Refractory ascites
- Spontaneous bacterial peritonitis
- Hepatorenal syndrome
- Refractory hepatic encephalopathy
- Recurrent variceal bleeding despite therapy

May be on waiting list for transplant. Will be discharged from hospice if donor found

Amyotrophic Lateral Sclerosis

- Dyspnea at rest with respiratory rate > 20
- Orthopnea
- Use of accessory respiratory muscles
- Frequent awakening
- Paradoxical abdominal motion
- Weakened cough
- Reduced speech/vocal volume
- Daytime somnolence
- Unexplained headaches, confusion, anxiety, nausea
- Dysphagia with progressive weight loss of at least 5% of body weight with or without gastrostomy tube

Recent CMS Clarifications

- Failure to Thrive and Debility are no longer considered acceptable primary diagnosis (may be secondary diagnosis)
- Primary and related (contributing to terminal prognosis) and secondary diagnoses must be coded
- Medicare D - “unrelated” meds clarification

What if prognosis is uncertain, goals change, or patient improves after admission to to hospice

- We admit patients based on *likely prognosis* if progresses with usual course
- If goals change, pts may revoke hospice benefit
- After six months on hospice, medical director visit required to reassess eligibility
- If continues to be eligible, medical director visit and recertification every two months
- If no longer eligible (at any time) we are required to discharge; but we keep the door open to reassess eligibility. We explain indicators of future decline to pts / caregivers upon discharge

- These are guidelines **only**
- You know your patient best
- Some patients may not fit *all* of the criteria and still be appropriate for hospice care
- Eligibility is determined by the hospice team
- MaineGeneral Hospice will evaluate ***any*** patient you may feel is eligible for hospice care
- Evaluations are provided without billing, for patients in any setting (home, long-term care facility, hospital)

Hospice/palliative intent of treatment assessed based on relief of current symptoms, rather than goal of prolonging life at expense of comfort

- What symptoms will be alleviated by the proposed treatment?
- What is the intended outcome?
- How can we determine if the outcome has been achieved and in what time frame?
- Have potential risks and side effects been explained to pt/family and does the pt want the treatment?
- What other alternative measures have been or could be attempted to alleviate symptoms?

Some common questions:

- Could a hospice patient receive
  - artificial hydration?
  - antibiotic therapy?
  - transfusions?
- Could a patient with an order to "Attempt CPR" be admitted to hospice?