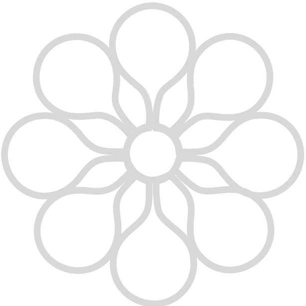
The Palliative Response

F. Amos Bailey, M.D.



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Acknowledgments

The Palliative Response represents the encouragement and support of many individuals who deserve recognition and who, I hope, will be honored by this work. I owe foremost gratitude to the patients who have been my primary teachers over the last 15 years. In the classrooms of their homes and hospital rooms, they have taught me much! It is a great privilege to be invited into a home; it is really being invited into a life. For allowing me that privilege, I thank Ms. M., my first hospice patient about whom I write in the Preface, and the over 2000 people on whom I since have made house calls. Palliative-care inpatients, first at the Balm of Gilead Center at Cooper Green Hospital and now at the Safe Harbor Project at the Birmingham Veterans Administration Medical Center, have all been wonderful educators. It is my honor to pass on their many lessons.

Dr. William Dismukes, Residency Director at UAB Health Systems, planted the seed for this book in 1999 when he asked that all Balm of Gilead patients be assigned to residents, and invited me to devote the final 10–15 minutes of each morning report to palliative care. Suddenly, I had a forum in which to talk about palliative care, and these talks gradually became *The Palliative Response.* My appreciation goes to the residents and medical students assigned to the Cooper Green Hospital Medical Service, who have listened and responded to these talks for the last four years.

My deep appreciation goes to Cooper Green Hospital and its former CEO Dr. Max Michel, who believed that we could create the Balm of Gilead Center as a site of excellence for End-of-Life care and training, and to all my colleagues at the Balm of Gilead and the Birmingham Area Hospice. Together we believed in a vision, and together we nurtured the vision into excellent care in the hospital and hospice of a public health system. Palliative Specialist/Nurse Practitioner Edwina Taylor, RN, CRNP; Project Director James Bolden, MPA, MT (ASCP); Charge Nurse Barbara Sunday, RN; and Community Coordinator Carol Padgett, PhD were instrumental in helping shape the Balm of Gilead into a community of caring at the End of Life.

Dr. Ira Byock and the Robert Wood Johnson Foundation, who selected Cooper Green Hospital and the Balm of Gilead as a demonstration project for Promoting Excellence in End-of-Life care, have offered unwavering support. Their emphasis on dissemination has inspired me to find ways to share the things we have learned and are continuing to learn about palliative care. Dr. Byock's focus on the potential at Life's End for growth in both patients and their caregivers sustains my motivation and guides my interactions.

Carol Padgett has helped organize my material while lending her insights as a keen observer of palliative patients, the human condition, and my interactions with patients, families, staff, and students.

My wife Marci and my children Mandy, Patrick, and Lydia faithfully sent me to my desk to write and faithfully appeared with technical support when the computer went on the fritz. My deepest gratitude, however, is reserved for their moral support, which has made all the difference.

— Dr. F. Amos Bailey,
Birmingham, September 2003

About the Author

In his preface to *The Palliative Response* the author poses the apparent paradox of growth at the end of life. To track the career of F. Amos Bailey is to examine a paradigm of professional growth. This career has taken him from his training as a medical oncologist to a practice in a small Appalachian community to an inner-city public hospital (where he founded the Balm of Gilead, an inpatient hospice facility) to a hospital for veterans. Through those transitions F. Amos Bailey has "morphed" from a simple practitioner of the healing arts into an icon for a new model of medicine's primary mission, the relief of human suffering.

Along the way, Dr. Bailey has become a teacher. He is, however, quite unlike the typical clinical educators who populate the corridors of modern teaching hospitals. Many of them are drawn to their work by a love of the academic environment and a fascination with the process of learning. F. Amos Bailey has been compelled to teach by the desire to advance the mission of palliative care and the need to touch more patients whose suffering needs his balm.

In an era when translation research is a key phrase for priority funding, F. Amos Bailey is perhaps the ultimate "translationalist." He has taken a body of clinically relevant knowledge from multiple domains and demonstrated how to apply it at the bedside in new way. Through this book he shows us how we can be better doctors.

F. Amos Bailey lives and grows in Birmingham with his wife Marci, and their children Mandy, Patrick, and Lydia. He currently practices his art at the VA Medical Center, where he directs the Safe Harbor Palliative Care Project.

— Dr. John I. Kennedy, Jr.

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Growing Pains

> *Maslow, Erickson, and Piaget each told us*
> *that human development is a lifelong process.*
> *I think it simply turns out that they were right.*
> *—Ira Byock, M.D.*

Growth at the Life's End? Such an idea initially might sound like an oxymoron. Life's End is, after all, a euphemism for Death. What could growth and death have to do with each other? I find part of the answer to that question in the concept of "growing pains." Some children experience pain in their bones at times in their lives when the growth is rapid, sudden and unexpected. When nothing else can explain the pain, we shrug and diagnose "growing pains."

This palliative-care manual is the fruit of "growing pains." In 1989, I moved to Beckley, West Virginia. I had completed training in Medical Oncology and had chosen to practice in a little Appalachian town to test my mettle and ability. Nothing in ten years of training, including a Medical Oncology Fellowship, had prepared me for the immediate turn that my professional life took toward providing care where there can be no cure. A patient, guided by a women's magazine and the wisdom of personal experience, taught me more about caring for the dying than I had learned from mentors guided by medical texts and the tenets of professional practice. Only when I happened upon the *Oxford Textbook of Palliative Medicine* did I recognize that "the suffering paradigm" had been the template over our discussions.

During my first month of private practice in West Virginia, a nurse and social worker asked me to serve as Medical Director for the hospice they hoped to start, assuring me that my duties would include only "signing some papers and writing a few prescriptions for pain medicine." During my second month, I was summoned to the home of Ms. M., who a year earlier had noticed numbness in her right hand. The CT scan had shown a tumor and the biopsy had confirmed its malignancy. Although radiation had held things in check for a few months, the numbness recurred and the repeat scan only confirmed what everyone knew was the recurrence of her cancer and the beginning of the end. Ms. M. read about hospice in "a women's magazine," requested a referral, and identified me as her "new doctor." Following the article's description of hospice care, which she was sure included house calls, Ms. M. was now demanding that her new doctor see her at her home.

With great trepidation, I made my way to her residence. What could I do for her? How could I help her in her own home? In ten years of training, I had received no formal instruction in caring for the dying. I had never referred a patient to hospice and had never heard the words "palliative care." On more than one occasion, I had witnessed patients dying while chemotherapy was being infused into their veins.

Entering Ms. M.'s home, I found a moon-faced bald woman propped in her chair and gazing into her backyard. Ms. M. was gracious and introduced me to her family. I dealt with a few minor adjustments in her medicines. And then she asked me what might happen. She discussed concerns about her children and about unfinished tasks, her interest in meditation and her childhood Catholic faith. She spoke of sadness and fears and, as we ended, told me how much I had helped and asked me to return soon. I visited Ms. M. for the next few months, until she died one cold fall night in her own home surrounded by her family.

I now understand my experience with Ms. M. as one of pain and growth for all who were involved. For me it was an epiphany. Over the next few years, amazed at how much better my dying patients fared at home than in the hospital, I strove to arrange for them to be discharged so that their suffering could be eased; and my clinical interventions in the hospital and clinics became tempered with home-style comfort care. All the while, I remained frustrated at the host of barriers that prevented greater application during hospital care of lessons learned from home care.

I have worked with many teachers since Ms. M. They have included my patients and colleagues in West Virginia, later at the Balm of Gilead Project at Cooper Green Hospital, and now at the Birmingham Veterans Administration Medical Center. This palliative-care manual is a distillation of some of the lessons I am learning.

Life's End can be a time of growth for each of us. Persons who are facing a life-threatening or terminal illness have been "dying" since the day they were born. Now, however, that reality thrusts its way to center stage and demands attention. The dying process can be a time of personal growth for these persons, their families and all with whom they come in contact. Dying persons and their communities grow as they accommodate the changes that are inevitable as death approaches. Palliative care can help each of us to experience personal growth in the light of Life's End. No one can make anyone grow. However, excellent end-of-life care—care that alleviates some of the physical, emotional, social, and spiritual suffering of Life's End—can allow patients, families, and their community of caring to grow and even blossom.

About This Book

As Medical Director of the Balm of Gilead Palliative Care Unit at Cooper Green Hospital, I supervised the General Internal Medicine residents who followed all patients admitted to the unit. The need for basic education in palliative care became clear shortly after the initiation of "palliative work rounds" during the final 15 minutes of the residents' Daily Morning Report. The chapters in this manual are the fruits of this opportunity to introduce new physicians to key dimensions of palliative care.

The manual's topics, designed for presentations of 12–15 minutes, cover management of physical symptoms and emotional, spiritual, and social issues common in end-of-life care. The manual offers guidance for specific palliative roles, such as sharing bad news, conducting a family conference, and making a death pronouncement. Chapters on specific diseases review common symptoms, end-of-life manifestations, and prognostic signs that might prompt referral to palliative care and hospice.

Each chapter opens with annotated **Key Points** from the 12–15 minute discussion and continues with a more detailed **Handout.** Each chapter concludes with **Selected Readings** that direct the student to references for further study on the chapter's topic.

The manual is appropriate as a basic classroom text for students and as a tutorial guide for residents and fellows in Palliative Medicine rotations. Its form facilitates selecting relevant sections for integration into classroom teaching or for review by rounding groups or consulting residents.

Five **Provider Pocket Cards** accompany the manual:

Consider Palliative Medicine outlines the conditions and goals warranting palliative-care consultation.

Analgesic Dosing is an aid for pain management.

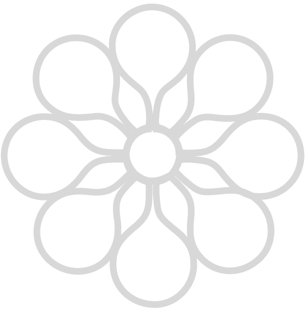
Sharing Bad News/Family Conference offers a procedure for speaking with patients and families about realities and decisions associated with Life's End.

Last Hours of Life suggests orders appropriate for patient comfort and family support.

Guidelines for Death Pronouncement leads the physician through the interpersonal and technical aspects of pronouncement, documentation, and follow-up family contacts.

My goal in developing *The Palliative Response* has been to offer a concise and accessible package suitable for palliative-care instruction and review in a variety of settings. My larger hope is that this effort will help bolster the competence, confidence, and commitment of medical providers to integrate *The Palliative Response* into daily clinical practice. I would appreciate feedback and constructive criticism from colleagues so that future revisions will reflect the ongoing refinement of palliative principles and practice.

Introduction to Palliative Care



Introduction to Palliative Care

Key Points

1. Palliative Care is a holistic response to suffering in the physical, emotional, social, and spiritual domains.

2. It is appropriate to integrate aggressive palliative management of symptoms into the care of patients receiving disease-modifying therapy.

3. Ninety percent of Americans would prefer to receive care at Life's End in their homes rather than in hospitals or nursing homes.

4. Instead, 50% of persons dying in the United States die in hospitals, 25% in nursing homes, 15% in personal homes, and 10% suddenly outside the hospital.

5. Home Hospice is a Medicare-defined benefit program that provides palliative care for some patients at home. Only 15–20% of dying persons are referred to hospice, and usually for less than the last month of life.

Introduction to Palliative Care

Suffering Paradigm

Social

Physical

Suffering

Emotional

Spiritual

End of Life in America:
What Do People Want?

Gallup Poll Results:
Nine out of 10 people would prefer to die at home if terminally ill with six months or less to live

70% would seek hospice care
62% would seek curative care

End of Life in America:
Where/How Do We Die?

- 15% die at home
- 10% die unexpectedly
- 25% die in nursing homes
- 50% die in hospitals

Why People Die
Causes of Death

- Heart Disease
- Cancer
- Stroke

Account for 67% of the deaths in people 65 years of age and older

Palliative Care
What Is It?

- Prevention and relief of symptoms
- Attention to emotional and spiritual needs
- Care for the patient and family as a unit
- Sensitive communication, goal setting and advance planning
- Interdisciplinary care
- Services appropriate to the various settings in which people die

Hospice
What Is It?

- A program to provide palliative care when life expectancy is six months or less
- Covered by Medicare and Medicaid
- Covered by private insurance plans with enhanced home-care benefits

Physical Suffering:
The Palliative Response

- Pain and multiple non-pain symptoms

  Treat pain; it is frequently undertreated.

  Assess/treat other sources of physical distress.
- Symptom prevention

  Foster compliance with treatment.
- Advance planning

  Collaborate with patient and caregivers.

  Anticipate and plan for likely events.

Emotional Suffering:
The Palliative Response

- Depression
- Anxiety
- Delirium
- Loneliness

Social Suffering:
The Palliative Response

- Limited income
- Lack of insurance

  Insurance often does not cover prescription medicines and home health services.
- Inadequate housing
- Social isolation
- Caregiver fatigue

Spiritual Suffering:
The Palliative Response

- Loss of hope
- Inability to sustain relations with faith community
- Search for meaning

The Palliative Response

Every physician
needs to know
the palliative response

Selected Readings

Palliative Care Overview

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In Search of a Good Death

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1.1 Anorexia

Key Points

1. Anorexia is a manifestation of the underlying disease.

   Anorexia is not the cause of the patient's terminal condition. However, most families and physicians express this erroneous belief in statements such as, "If only he would eat, he would get better!"

2. Family and friends are often more concerned than the patient about anorexia.

   Providers can help family and friends find alternative ways to express their love and concern, so that eating does not become an area of conflict.

3. Anorexia may have multiple causes related to poor symptom control.

   The provider can look for reversible causes of anorexia, such as poorly controlled pain and other physical symptoms, and can seek the help of dietary professionals in selecting palatable foods. A "cardiac prudent diet" is probably no longer necessary.

4. Anorexia may respond to an appetite stimulant like dexamethasone.

   Dexamethasone is a preferred appetite stimulant. It is effective, inexpensive, and may have additional benefits such as serving as an adjunct for pain control, lifting the patient's mood, and addressing asthenia. Megestrol is expensive ($300–$500/month), not very effective, and results in no identifiable improvement in quality of life.

5. Anorexia, when severe, often results in the use of IVF, TPN, or tube feedings.

   These treatments may be very appropriate to bridge and support someone until normal eating can resume. For most people at the Life's End, these treatments can cause:

   1) iatrogenic harm because of infections, fluid overload, and aspiration pneumonia;

   2) pain and discomfort from the placement and maintenance of IV and tubes;

   3) increased use of restraints to protect IV lines and feeding tubes.

Anorexia

The Palliative Response

Anorexia Is a Symptom

Anorexia is a common symptom at Life's End.

Decreased intake is nearly universal in the last few weeks to days of life.

The Role of the Physician

- Look for reversible causes
- Consider the use of appetite stimulants
- Provide accurate and helpful information
- Help family members identify alternative methods of expressing love
- Ensure that any IV or tube feedings are safe, effective, and consistent with Goals of Care

Dietary Management

- Involve the patient in menu planning
- Offer small portions of patient's favorite foods
- Offer easy-to-swallow foods
- Try sweets
- Avoid foods with strong smells, flavor, or spices, unless patient requests

Responding to Family Concerns

- Family members and caregivers are more concerned about lack of appetite and may harass the patient about decreased intake
- Anticipate family concerns and initiate family discussion about decreased appetite
- Be prepared to discuss and review this symptom every time you meet with family
- Demonstrate willingness to look for reversible causes and to use appetite stimulants

Educating Patient and Family

about progression of the underlying illness and its effect on appetite

- Anorexia is a symptom of the disease
- The patient is not starving
- Forced feeding often causes discomfort
- Artificial feeding usually does not prolong life and may shorten it
- Patients are usually not uncomfortable from decreased intake and can live for long periods on little food

Reversible Causes of Anorexia
Differential Considerations

- Poorly controlled pain and non-pain symptoms
- Nausea and vomiting
- GI dysmotility (gastroparesis)
- Oral infections such as thrush or herpes simplex
- Xerostomia (dry mouth)

Reversible Causes of Anorexia
Differential Considerations

- Constipation and urinary retention
- Medications such as iron supplements
- Chemotherapy and radiation
- Depression and anxiety
- Gastritis and Peptic Ulcer Disease

Consider an Appetite Stimulant
Alcohol

- Wine, sherry, and beer have significant calories and are well-known appetite stimulants
- Consider using if consistent with culture and heritage and if no history of past alcohol abuse
- Many people who had used alcohol routinely before they became ill have the impression that they must now not drink alcohol at all

Consider an Appetite Stimulant
Cyproheptadine (Periactin)

- This antihistamine has the side effect of weight gain
- Has been used to treat anorexia nervosa
- Not highly effective and may be more placebo effect than active drug
- Is not likely to be helpful at Life's End

Consider an Appetite Stimulant
Megestrol (Megase)

- Approved for the treatment of AIDS wasting
- Dose for wasting is megestrol suspension 800mg QD
- Expensive—approximately $350/month
- Major side effects are Pulmonary embolism nausea and vomiting

Consider an Appetite Stimulant
Megestrol (Megase)

- In patients with cancer, the use of megestrol was not associated with any documented improvement in QOL or survival
- Usually not recommend for anorexia at EOL

Consider an Appetite Stimulant

Dexamethasone (Decadron)

- Dose of 2–4mg at breakfast and lunch
- Can tell within a few days to a week if effective
- Inexpensive
- May also have beneficial effects on pain, asthenia, and mood
- Causes less fluid retention than other corticosteroids

Consider an Appetite Stimulant

Dexamethasone (Decadron)

- Use caution with history of diabetes mellitus
- Usually not concerned in the EOL setting about long-term complications of steroids
- May be a good choice in COPD patients who have become steroid dependent

Consider an Appetite Stimulant

Dronabinol (Marinol)

- Usually used in young patients with past experience with marijuana
- Expensive—up to $500/month
- Requires DEA Schedule III
- Usually used in HIV or as part of treatment protocol with chemotherapy

Artificial Nutrition at Life's End

Tube Feeding

- Tube feeding and forced feeding in terminally ill patients have not been shown to prolong life
- Nasogastric and gastrostomy tube feedings are associated with:

  Aspiration pneumonia

  Self-extubation and thus use of restraints

  Nausea and diarrhea

  Rattling and increased respiratory secretions

Artificial Nutrition at Life's End

Total Parenteral Nutrition (TPN)

Meta-analysis of 12 randomized trials in cancer patients (1980s)

- Decreased survival
- Decreased response to chemotherapy
- Increased rate of infections

Is anorexia ever
a protective mechanism?

Artificial Nutrition at Life's End

Consider Potential Burdens

Tube feeding and IV hydration often increase secretions, ascites, and effusions, which require additional treatments.

Always ask:
"Are these kinds of treatments in line with the Goals of Care?"

Selected Readings

Myths, Theories, and Decision-Making

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1.2 Asthenia (Fatigue)

Key Points

1. The subjective and multidimensional symptoms of Asthenia cause ongoing distress in more than 90% of people at Life's End.

   Asthenia is prevalent with chemotherapy or radiation and persistent or progressive cancers, universal with the biologic response modifiers, and common with many other illnesses with end organ failure.

2. Assess fatigue by asking patient about its presence, severity, interference with activities, level of concern, and impact on Quality of Life.

   Cognitive complaints include short-term memory loss and diminished concentration and attention. Emotional complaints include marked reactivity to feeling fatigued and decreased motivation and interest in usual activities. Practical complaints include difficulty completing tasks, struggle to overcome inactivity, and post-exertional malaise lasting several hours.

3. The pathophysiology of fatigue requires differential diagnosis that evaluates also for progressive cancer, intercurrent systemic disease, and other causal factors.

   Such factors include sleep disorders, deconditioning and immobility, central-acting drugs, chronic pain or other poorly controlled symptoms, depression and anxiety.

4. Manage fatigue according to stage of underlying illness, effects of treatment, changing Goals of Care, and life expectancy.

   Stop nonessential medications. Try to avoid invasive enteral and parenteral routes when hydrating or feeding. Look for easily correctable metabolic disorders. Hydration and food supplements may help.

5. Dexamethasone is the preferred steroid at Life's End and may be helpful for fatigue in the late stages of illness.

   Its effect may last 2–3 months, and it has less mineral-corticoid effect. Dexamethasone 4mg po ~ Prednisone 15mg po.

6. Counsel fatigued patient to set realistic goals, conserve energy for most important activities, exercise, and practice good sleep hygiene.

Asthenia (Fatigue)

The Palliative Response

Impact

- Reported by > 90% of persons at Life's End
- Often most distressing symptom, even compared to pain or anorexia
- Limits activity
- Increases dependency
- Diminishes sense of control, and self-determination

Prevalence

- Universal with biologic response modifiers
- > 96% with chemotherapy or radiation
- > 90% with persistent or progressive cancers
- Common with many other illnesses with end organ failure

  (Congestive Heart Failure, Chronic Pulmonary Disease, Chronic Renal Failure, General Debility)

Characteristics

- Subjective
  - *Severity*
  - *Distress*
  - *Time Line*
- Multidimensional
  - *Weakness and or lack of energy*
  - *Sleepiness*
  - *Difficulty concentrating*

Patient Experience

Physical Symptoms

- Generalized weakness
- Limb heaviness
- Sleep disturbances
  - *Insomnia*
  - *Hypersomnia*
  - *Unrefreshing/nonrestorative sleep*

Patient Experience

Cognitive Symptoms

- Short-term memory loss
- Diminished concentration
- Diminished attention

Patient Experience

Emotional Symptoms

- Marked emotional reactivity to fatigue
- Decreased motivation/interest in usual activities

Patient Experience

Practical

- Difficulty completing daily tasks
- Struggle to overcome inactivity
- Post-exertional malaise lasting several hours

Differential Diagnosis

Potential Mechanisms of Asthenia Associated with Cancer

- Progressive disease
- Cytokines
- Decreased metabolic substrates
- Change in energy metabolism
- Treatments

  Chemotherapy, radiation, surgery, and biologics

  Effects are cumulative and can last for months

Differential Diagnosis

Intercurrent Systemic Disease

- Anemia
- Infections
- Malnutrition
- Dehydration and electrolyte imbalance

Differential Diagnoses

- Sleep disorders
- Deconditioning and immobility
- Central-acting drugs
- Chronic pain/other poorly controlled symptoms
- Depression
- Anxiety

Assessment

- Do you have fatigue?
- How severe is your fatigue? (Use analog scale)
- Does fatigue interfere with activities?
- Are you worried about the fatigue?
- Does fatigue impact your Quality of Life? How?

Goals of Care

- Fatigue usually remains a concern throughout stages of illness at Life's End (although may respond in part to treatment)
- Modify Goals of Care by stage of illness
  - *Prolongation of life or cure of disease*
  - *Improving function*
  - *Comfort and supportive care*

Effect on Fatigue
Disease-Modifying Therapies

- Some therapies may worsen fatigue
  - *Chemotherapy or radiation for cancer*
- Others may improve fatigue
  - *Dialysis for renal failure*
  - *ACE for congestive heart failure*
  - *Oxygen for hypoxia*
  - *Opioids for pain management*

Anemia in Cancer Patients
Benefits of Erythropoetin (EPO)

Placebo Controlled Trial
Subjects randomized to EPO
Hemoglobin 8–10g/dl

- Increased hemoglobin
- Decreased use of transfusion
- Increased Quality of Life
- Effects independent of tumor response

Anemia in Cancer Patients
Burdens of EPO

- Requires injections
  - *(EPO 10,000 units subcutaneous 3 times a week)*
- Expensive and insurance may not cover $400–$500/month
- Variable effectiveness
  - *Takes weeks to be effective*
  - *May require higher doses for effect*
  - *Not always effective*

Management of Fatigue

- Stop all nonessential medications
- Look for easily correctable metabolic disorders (e.g., decreased potassium or magnesium levels)
- Hydration and food supplements may be helpful (usually try to avoid invasive enteral and parenteral routes)

Management of Fatigue
Associated with Depression

- Symptoms of major depression
  - *Depressed mood*
  - *Anxiety*
  - *Irritability*
- Treatment (choice depends on life expectancy)
  - *SSRI's*
  - *Counseling*
  - *Psycho-stimulants*
  - *Supportive management*

Management of Fatigue
Dexamethasone

- May be helpful in late stages of illness
- Effect may last for 2–3 months
- A preferred steroid in this setting

  Less mineral-corticoid effect

  Prednisone results in more edema

Dexamethasone 4mg po ~
Prednisone 15mg po

Use of Dexamethasone

- Dosage

  Dexamethasone 4–8mg q am

  May increase to 16mg qd (equivalent to Prednisone 60mg)

  Usually no advantage to higher doses

  Avoid nighttime dosing because of insomnia
- Side effects

  Watch for side effects, although they are usually well tolerated

  Long-term complications usually not a concern

Management of Fatigue
Sleep Hygiene

- Use Trazedone (25–100mg q hs) for insomnia instead of benzodiazepine
- Avoid napping
- Avoid stimulants in the evening
- Avoid alcohol before bed
- Exercise during the day (even sitting up in chair)

Management of Fatigue
Education/Counseling

- Goal setting

  Assist patient to set realistic goals.
- Energy conservation

  Counsel saving energy for most important activities.
- Assistance with activities of daily living

  Enlist the assistance of family.

  Home Health Aide and Homemaker PT/OT evaluation for appliances and exercise

Management of Fatigue
Exercise

- Physical Therapy (PT)

  Evaluate appropriateness of PT to improve quality, and perhaps even quantity, of life for patients with better prognosis.
- Up Out of Bed

  Can significantly impact QOL for patients at Life's End

  Range of motion to maintain flexibility

Asthenia at Life's End

Fatigue, weakness, and lack of stamina cause suffering in > 90% of persons at Life's End.

Selected Readings

Overview of the Symptom of Asthenia

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1.3 Constipation

Key Points

1. Assess all patients at Life's End for constipation. Evaluate for obstipation after 48 hours without a bowel movement.

   Over half of patients at Life's End suffer from constipation. Inquire about bowel habits (frequency, consistency, and previous habits), other symptoms (nausea/vomiting, abdominal pain, distention, anorexia, and diet), and attempted interventions. Obstipation is such severe constipation and impaction that there is a functional bowel obstruction.

2. Determine the cause of constipation by rectal digital exam, abdominal exam, and neurological exam. Radiographic and laboratory studies may be helpful.

   Rectal exam: Evaluate for impaction, hemorrhoids, or other problems. Abdominal exam: Evaluate for bladder distention, hernias, and masses.

3. Asthenia (fatigue) can play a role in constipation at Life's End by disrupting the normal gastrocolic reflex and limiting activity and privacy.

   Support bowel routine. Assist patient to be up. Assist to the toilet when urge occurs. Serve hot beverages. Assure as much privacy as possible.

4. Differential diagnosis should consider medication side effects, concurrent diseases, and environmental factors.

5. Physicians should treat constipation rather than withholding opioids that may be contributory.

6. Large-bowel stimulants and interventions to support bowel routine are key to managing constipation in the palliative-care setting.

   Over 80% of palliative patients, and nearly all on opioids, require laxative therapy. Use Bisacodyl (Dulcolax) 1–4 tablets a day or Senna 2–8 tablets a day. Senna can be much more expensive—be guided by patient preference.

Constipation

The Palliative Response

Overview of Constipation

- Definition

  The infrequent passage of small hard feces
- Prevalence at Life's End

  Over half of palliative care patients report constipation as a troubling symptom
- Intervention

  >80% of patients at Life's End need laxatives

  Nearly all patients on opioids need laxatives

Assess Constipation
in All Palliative Patients

- Bowel Habits

  Frequency and consistency

  Previous bowel habits
- Other Symptoms

  Nausea/vomiting

  Abdominal pain, distention, anorexia
- Interventions

  What has been tried and what helps?

Assess for Impaction

- General Rule

  Evaluate for constipation and impaction after 48 hours with no bowel movement
- Obstipation

  Functional bowel obstruction from severe constipation and impaction

Asthenia (Fatigue)
as Contributor

- Disruption of normal gastrocolic reflex

  Gastrocolic reflex produces urge to defecate usually within an hour after breakfast and lunch

  Urge will resolve in 10–15 minutes if suppressed

  Reflex may disappear if suppressed for several days
- Limited activity

  Often cannot walk to the bathroom
- Limited privacy

  Prevents or deters use of bedside commode/bedpan

Support Bowel Routine

- Assist patient with being up
- Hot beverage if known to be helpful
- Assist patient to toilet when urge occurs
- Assure as much privacy as possible

Rectal Digital Exam

- Tumor
- Constipation
- Impaction
- Local fissures
- Hemorrhoids
- Ulcers

Abdominal Exam

- Bladder distention
- Urinary retention
- Obstruction
- Hernias
- Masses

  Tumor

  Impacted stool

Additional Evaluation

- Neurological exam

  Impending cord compression
- Consider flat plate and upright X-rays

  High impaction

  Bowel obstruction

  Gastric outlet obstruction
- Lab evaluation

  Hypercalcemia

  Hypokalemia

Differential Diagnosis

Medication Review

- Opioids
- Medications with anticholinergic effects
- Diuretics
- Iron
- Anticonvulsants and anti-hypertensives
- Vincristine and platinols
- Antacids with calcium and aluminum
- Ondanstron

Continuation of Opioids

- Treat constipation rather than withdrawing opioids
- Never stop opioids as response to constipation if patient requires opioids for relief of pain or other distressing symptoms

Differential Diagnosis

Concurrent Diseases

- Diabetes
- Hypothyroidism
- Hyperparathyroidism
- Hypokalemia and hypomagnesemia
- Hernia
- Diverticular disease
- Anal fissures and stenosis
- Hemorrhoids

Differential Diagnosis

Environmental Factors

- Decreased food intake
- Dehydration
- Weakness and inactivity
- Confusion
- Depression
- Structural barriers to bathroom or toilet

Laxative Treatments

- Softeners
  Surfactants like docusate (Colase)
- Osmotic
  Lactulose
  Sorbitol
- Bulking agents
  Metamucil (usually not appropriate at EOL)
- Saline laxative
  Magnesium citrates or Milk of Magnesia (MOM)

Large Bowel Stimulant

Constipation must be managed in the palliative-care setting

- Bisacodyl (Dulcolax) 1–4 tablets a day
- Senna 2–8 tablets a day
  Can be much more expensive than bisacodyl
  Be guided by patient preference

Algorithm for Treatment

Rectal Exam — Soft feces

Impaction

Consider oil retention enema to soften feces

Spontaneous defecation of Impaction
Soft feces

Manual Disimpaction
Consider sedation with Lorazepam
Soft feces

Algorithm for Treatment

Soft feces

Base choice of treatment on:

- Patient preference
- Urgency for bowel movement

Oral Biscodyl or Magnesium Citrate
Rectal vault empty

Fleets Enema or Biscodyl Suppository
Rectal vault empty

Algorithm for Treatment

Rectal vault empty

Bisocodyl 2–4 QD
May add MOM 30 cc QD

Goal:
Bowel movement every 48 hours

Increased risk of impaction if interval between bowel movements > 48 hours

Address Environment:
Privacy
Gastrocolec reflex
Assistance with feeding and hydration
Access to toilet
Maximize activity

Selected Readings

Overview

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1.4 Dyspnea

Key Points

1. Dyspnea is the subjective sense of breathlessness or smothering.

   Patients can self-report the severity of their dyspnea using a scale similar to the pain scale. Hypoxia and dyspnea are not always concordant; patients with hypoxia may or may not have dyspnea. Dyspnea is reported by over half of patients at Life's End.

2. Dyspnea may have multiple causes.

   Palliative care does not exclude the search for and treatment of the underlying causes of dyspnea. Palliative care recognizes that the causes of the dyspnea may not be responsive to treatment or that the burden of treatment may outweigh the benefit.

3. Oxygen alone often does not relieve dyspnea.

   Oxygen is a potent symbol of medical care. However, patients routinely can neither tolerate, nor have available in the home, more than 2–5 L of Oxygen by nasal prong. Oxygen alone is usually not adequate treatment to relieve chronic dyspnea.

4. Low-dose opioids can often safely relieve symptoms of dyspnea.

   Low doses of short-acting oral opioids often can reduce dyspnea without sedation or respiratory depression.

5. Dyspnea causes chronic anxiety, which may respond to low-dose benzodiazepines.

6. Dyspnea often responds to non-pharmacological interventions better than to oxygen.

   Many patients find that a fan blowing cool air on the face is more effective for the relief of dyspnea than a 100% non-rebreather mask.

Dyspnea

The Palliative Response

The Experience of Dyspnea

- Shortness of breath
- Breathlessness
- Smothering feeling
- Suffocation
- Present at rest
- Worsened by activity

Diagnosing Dyspnea

- Self-report is the key
  - *To detecting dyspnea*
  - *To appreciating the severity of dyspnea*
- Use analog scale to help people self-report severity of shortness of breath
  - *Now?*
  - *At the worst?*
  - *At the best?*
  - *After treatment?*

Diagnosing Dyspnea

- Prevalence may be greater in patients with life-threatening illness
  - *COPD*
  - *CHF*
  - *Lung cancer*
- Blood gas, oxygen saturation, and respiratory rate do not substitute for patient's self-assessment and report of dyspnea

Fix It* versus *Treat It

Paradigm

- Look for reversible causes
- Help patients, families, and colleagues consider the burden of treatment of the underlying cause versus the benefit of treatment

Fix It* versus *Treat It

Paradigm

- Treat dyspnea as a symptom while looking for a reversible cause
- The cause of the dyspnea may take some time to improve
- Often dyspnea does not have a reversible cause, yet patients do not have to suffer unrelieved dyspnea for the remainder of life

Potentially Reversible
Causes of Dyspnea

- Pneumonia and bronchitis
- Pulmonary edema
- Tumor and pleural effusions
- Bronchospasm
- Airway obstruction
- COPD
- Asthma
- Thick secretions

Potentially Reversible
Causes of Dyspnea

- Anxiety
- Pulmonary embolism
- Anemia
- Metabolic disturbance
- Hypoxemia
- Family and practical issues
- Environmental problems

Benefit versus Burden of Treatment

- It is always important to consider causes of dyspnea
- However, before deciding the extent of evaluation beyond history and physical, begin to weigh benefit versus burden of disease-modifying treatment.

Symptomatic Management
Oxygen

- Oxygen is a potent symbol of medical care
- Try to avoid mask

  Causes discomfort from sense of smothering

  Involves unpleasant accumulation of mucus and moisture

  Interferes with communication and oral intake

Symptomatic Management
Oxygen

- Use humidifier if using nasal prong
- Most people will not tolerate more than 2 l/m
- Be guided by patient comfort, not by oxygen saturation
- Home oxygen is usually provided by a concentrator, which cannot provide more than 5 l/m
- A fan or air conditioner may provide the same level of comfort

Symptomatic Management
Opioids

- Opioids are the most effective treatment for unrelieved dyspnea
- Central and peripheral effects
- Begin with small doses of short-acting opioids
- MS 5mg or Oxycodone 5mg orally q4 hours *Offer/May Refuse* is often a good starting point
- Use analog scale as in pain management to monitor effect

Symptomatic Management
Opioids

- Physicians are afraid people will stop breathing
- It may reassure wary colleagues of the safety of this approach to order *Give if respiratory rate of greater than 20/m*, since relief of dyspnea may not be related to decrease in rate

Symptomatic Management
Nonpharmacological

- Fan
- Keep environment cool, but avoid chilling patient
- Consider cool foods
- Reposition patient; allow to sit up in bed or chair
- Avoid environmental irritants
- Avoid claustrophobic settings
- Have a plan for the next episode of dyspnea to give patient and family sense of control

Symptomatic Management
Anxiolyics

- Anxiety may be a component for patients suffering with dyspnea
- Lorazepam (Ativan) is safe to combine with opioids for dyspnea

  0.5–1mg prn q2 hours may be helpful

  Some patients may benefit from scheduled doses

Dyspnea Review

- Dyspnea is common in patients referred to palliative care
- Dyspnea is also common in the general patient population
- Dyspnea can be effectively controlled in most patients whether or not referred to palliative care
- Visual analog scale is the best tool for assessing dyspnea and monitoring effectiveness of its treatment

Selected Readings

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Oral Morphine as Symptomatic Treatment

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Management of Dyspnea and Cough

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1.5 Insomnia

Key Points

1. Insomnia manifests as nonrefreshing sleep, difficulty falling asleep or maintaining sleep, or early morning awakening. It causes daytime sleepiness and poor concentration, diminished coping and QOL, and exhaustion in family and caregivers.

2. Insomnia is common and increases with age or illness.

   About 50% of advanced cancer patients report insomnia, and about 75% of patients admitted to a palliative-care unit require hypnotic medication.

3. Assessment includes differential diagnosis that considers treatment or medication side effects, poor sleep environment, mental disorders, primary sleep disorders, physical symptoms, and the effect of substances or substance withdrawal.

   Effects of sleep environment can include uncomfortable bed, lights, noise, odors, being awakened for vital signs or blood draws, blood transfusion, and monitoring devices or alarms. Substance effects many include use of coffee, tobacco, or caffeine, or withdrawal from alcohol or benzodiazepines. Medications requiring evaluation include steroids, albuterol, theophyline, and stimulants.

4. The physician assesses for insomnia by questions about its presence, chronicity, or acuteness, factors associated with sleep difficulties and efforts to address them, as well as inquiries about differential diagnoses.

5. Management of insomnia includes improving symptom control and identifying and treating contributory factors.

   Delirium, common at Life's End, may be mistaken for insomnia, and some insomnia medications can worsen delirium. The physician can stop unnecessary medications and move steroids and stimulants to morning doses. Sleep hygiene interventions include exercising earlier in the day, following a bedtime ritual, practicing relaxation techniques, and restricting use of bed to sleeping.

6. Trazedone is a common regimen based on the anecdotal experience of hospice programs.

   There is not good evidence about the medication most effective for insomnia. The Trazedone dose may vary from 25–100mg q hs.

Insomnia

The Palliative Response

What Is Insomnia?

- Manifestations

  Nonrefreshing sleep

  Difficulty falling asleep

  Early morning awakening

  Difficulty maintaining sleep

- Symptoms

  Daytime sleepiness

  Daytime lack of concentration

Prevalence

- Common in the population
- Increases with age or illness

  Advanced cancer

  ~ 50% of patients report insomnia Palliative Care patients

  ~75% of patients admitted to a palliative-care unit require a hypnotic medicine

Cycle

- Etiology

  Pain and other symptoms lead to insomnia

- Sequelae

  Insomnia exacerbates other symptoms and makes them harder to bear

- Effects

  Diminishes coping capacity

  Lowers reported QOL

  Exhausts family and caregivers

Differential Diagnosis

- Treatment side effects

  Diarrhea, nausea, instrumentation

  Chemotherapy induced mucositis, pain

- Poor sleep environment

  Uncomfortable bed, lights, noise, odors

  Awakened for vital signs, blood draws, etc.

  Blood transfusion

  Monitoring devices and alarms

Differential Diagnosis

- Mental disorders

  Depression, delirium, anxiety

- Substances

  Coffee, tobacco, caffeine

- Withdrawal from substances

  Alcohol, benzodiazepines, other drugs

- Medications

  Steroids, albuterol, theophyline, stimulants

Differential Diagnosis

- Primary sleep disorder
  Sleep apnea
  Restless legs syndrome
- Physical symptoms
  Pain, dyspnea, cough
  Diarrhea, nausea, pruritis

Assessment

- Do you experience insomnia?
- Chronic problem or new with this illness?
- What do you think makes it hard to sleep?
- What works and doesn't work to help?
- Depression or anxiety causing problems?
- Stimulants, like coffee or alcohol, before sleep?

Management of Insomnia

- Improve control of pain or other symptoms
- Identify and treat depression
- Identify and treat delirium
  Common at Life's End
  May be mistaken for insomnia
  Worsened by some insomnia medications

Management of Insomnia

- Support treatment for known primary sleep disorder
  E.g., CPAP for sleep apnea
- Review medications
  Stop unneeded medicines
  Administer steroids/stimulants in morning
  Counsel about caffeine, alcohol, tobacco

Management of Insomnia
Sleeping Environment

- Comfortable bed and position
- Appropriate lighting and noise level (some people need white noise)
- Reduce interruptions such as vital signs, medicine, blood draws, transfusions
- Reduce instrumentation and monitors with alarms

Management of Insomnia
Sleep Hygiene

- Exercise earlier in day
- Establish bedtime ritual
- Employ relaxation techniques
- Restrict use of bed
  Bed is for sleeping
  If unable to sleep, get out of bed

Medications for Sleep
Trazedone

- Lack of good evidence about most effective medication for insomnia

- Trazedone 25–100mg q hs
  - *Has become a common regimen*
  - *Problems with other medications*
  - *Positive anecdotal experience of hospice programs*

Medications for Sleep
Benzodiazepine Hypnotic

- Meant for short-term use (2 weeks or less)
- Tolerance develops rapidly
- May contribute to delirium
- Problems of withdrawal
- Short-acting forms—wake up in night
- Long-acting forms—daytime grogginess

Medications for Sleep
GABA/BZD Agents

- Examples
  - *Zalepion (Sonata)*
  - *Zolpidem (Ambien)*

- Comparison with benzodiazepine
  - *Act at same site*
  - *Same problems and precautions*
  - *Cost significantly more without clear benefit*

Medications for Sleep
Antidepressants

- Good choice if someone is depressed
- Trazedone
  - *Has become antidepressant of choice*
  - *Fewer side effects*
- Doxipen and Imipramine
  - *More sedating*
- Side Effects
  - *Constipation*
  - *Dry mouth*
  - *Orthostatis*

Medications for Sleep
Antihistamines

- Usually not drug of choice
  - *Short-term effect*
  - *Numerous interactions with other medications*
  - *May contribute to delirium*
- Benadryl is in many over-the-counter sleep aids
- Herbal or natural remedies untested

Review of Insomnia

- Assessment
  - *Often multifactorial*
  - *Reassess frequently*
- Treatment
  - *Treat underlying causes if possible*
  - *Use hypnotic medications if needed*
- Goals of Care
  - *Restful sleep*
  - *Improved QOL and daytime functioning*

Selected Readings

Savard, J. and C. Morin. “Insomnia in the Context of Cancer: A Review of a Neglected Problem.” *Journal of Clinical Oncology* 19 (2001): 14.

1.6 Nausea and Vomiting

Key Points

1. Nausea is a source of distress even if vomiting does not occur.
   Nausea is a complex symptom that may lead to vomiting by activation of the vomiting center and retroperistalsis. There are four major sources of input into the vomiting center. Patients often have more than one source of input.

2. Nausea may be due to fear and anxiety.
   Fear and anxiety can lead to anticipatory nausea.

3. Nausea may be due to increased intracranial pressure.
   Pressure may be due to metastatic or primary tumor, intracerebral bleed or trauma, hydrocephalus, or infection.

4. Nausea may be due to vestibular dysfunction.
   Vertigo may be due to inner-ear infection, sinus congestion, primary vertigo, or hyponatremia.

5. Nausea may be due to the action of drugs, uremia, hypercalcemia, or acidosis upon the chemoreceptor trigger zone.
   Multiple medications and metabolic disturbances can affect the chemoreceptor trigger zone. A careful review of medications is indicated. However, if individual needs the opioid for pain and dyspnea control, it is better to treat the nausea than to stop the opioid.

6. Nausea may be due to GI disorders such as constipation, obstruction, gastroparesis, gastritis, metastatic disease, hepatomegaly, or ascites.
   Prevention of constipation and use of a prokinetic like metochlopromide are key to managing this source of nausea.

Nausea and Vomiting

The Palliative Response

Nausea

- The unpleasant feeling that there is a need to vomit

- A source of distress even if vomiting does not occur

- Accompanied by tachycardia, increased salivation, pallor, and sweating

Retching and Vomiting

- Retching

  Spasmodic contractions of the diaphragm and abdominal muscle

  May lead to vomiting

  May persist after the stomach has emptied
- Vomiting

  Expulsion of the gastric content through the mouth

The Vomiting Center

- Tractus solitarus, reticular formation in the medulla
- Parasympathetic motor efferents

  Contraction of pylorsis

  Reduction of lower esophogeal sphincter (LES)

  Contraction of stomach
- Retroperistalsis

Input

Into the Vomiting Center

- Fear and anxiety

  May cause anticipatory nausea

- Increased intracranial pressure

  Metastatic tumor

  Primary tumor

  Intracerebral bleed/trauma

  Hydrocephalus

  Infection

Treatmen

- Fear and anxiety

  Lorazepam: 1mg q6–8 hours

  Counseling
- Increased intracranial pressure

  Dexamethasone: 4–10mg q6

  Mannitol infusion (short-term bridge to definitive treatment)

  Radiation therapy

  Neurosurgery

Input
Into the Vomiting Center

- Vestibular dysfunction (Vertigo)

  Causes: *Inner ear infection*
  Sinus congestion
  Primary vertigo
  Hyponatremia

  1st line treatment:
  Antihistamines
  Meclizine

  2nd line treatment:
  Anticholinergic
  Scopolamine
  Hyoscine

Input
Into the Vomiting Center

- Chemoreceptor trigger zone

  Drugs
  Opioids
  Digoxin
  Antibiotics
  Cytotoxics
  Anticonvulsants

  Uremia
  Hypercalcemia
  Acidosis

Input
Into the Vomiting Center

- Chemoreceptor trigger zone

  1st line treatment:
  Dopamine antagonist
  Haloperidol
  Prochlorperazine
  Metoclopramide

  2nd line treatment:
  5HT3 antagonist ondanstron

  Nonspecific
  Dexamethasone

Input
Into the Vomiting Center

- GI disorders

  Constipation
  GI obstruction
  Gastroparesis
  Gastritis (NSAID)
  Metastatic disease
  Hepatomegaly
  Ascites

Treatment
GI Disorders

- Relieve constipation
- Relieve obstruction
- Review medications

Treatment
GI Disorders

- H2 blockers or PPI
- 1st line treatment:

  Metoclopramide
- Consider

  5HT3
  Dexamethasone
  Bowel rest

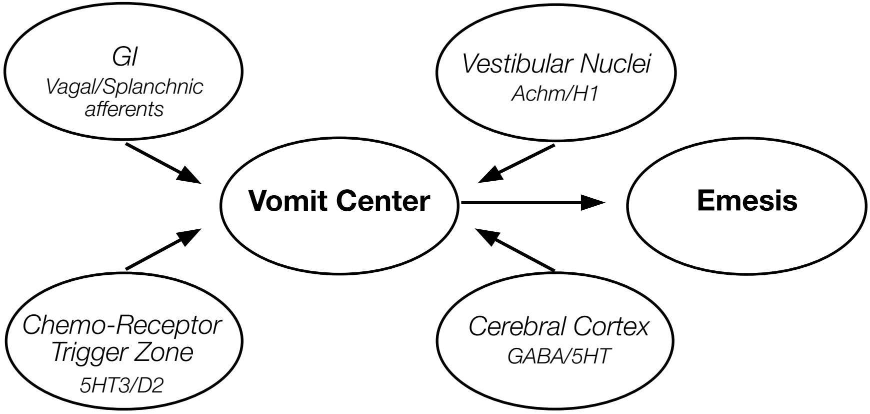
Treatment Plan

- Relaxing and nonstressful environment
- Medication after meals, except for anti-emetics
- Mouth care and topical anti-fungal prn
- Remove sources of offensive odors
- Small portions, frequent meals
- Monitor for constipation or bladder distention

Treatment Plan

- Dexamethasone as a non-specific anti-inflammatory
- Cannabinoids (Marijuana or Marinol)
- Some new atypical anti-depressants (Rimeron)
- When all else fails, go back to beginning
- If mechanical obstruction, may benefit from octratide (see plan of care for GI obstruction)

Input into Vomiting Center



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Overview

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Management

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1.7 Feeding by Mouth

Key Points

1. It is important to create a setting conducive to feeding by mouth.

2. Special eating procedures are helpful for patients with asthenia or neuromuscular disorders.

3. Encourage oral hygiene, treat for infection, and order dental work as needed. Treat taste disorders by addressing underlying disease and the symptom of bad taste.

4. Treat dry mouth from radiation with saliva substitute and frequent sips of water.

   When dry mouth is a side effect of medication, substitute drugs or reduce dosage if possible. Address dry mouth in the last hours of life by increasing liquids by mouth or involving family in mouth care.

5. Suspect and assess for Oral Candidiasis (Thrush) as cause of problems with eating. Viral infections and cold sores are usually caused by herpetic infection.

6. To manage Reflux Esophagitis, keep patient upright, serve small meals, and use prokinetic, H2 blockers, and proton pump inhibitors if needed.

7. Mucositis is a somatic type of pain that usually responds to opioid therapy.Treat Mucositis with oral lavage with soda water, "Magic/Miracle Mouthwash" or Viscous Xylocaine.

8. Difficulty with eating is common at Life's End, causes significant distress, and is often multifactorial. Careful and thoughtful evaluation can relieve suffering, improve Quality of Life, and increase oral intake in the majority of patients.

Feeding by Mouth

The Palliative Response

The Setting

- Environment—calm and unhurried
- Posture —upright (chair is preferable)

  Edge of bed preferable to in bed, but unstable
- Assistance from family or nursing staff

  Free nursing time by eliminating activities unnecessary at Life's End (e.g., frequent vital signs)
- Role of occupational therapy

  Special aids (sipper cups/wide-grip utensils)

  Straws increase risk of aspiration

Asthenia or Neuromuscular Disorders

Preparation for Eating

Posture

- Upright position
- Stabilize the head

Meal

- Small frequent meals
- Bite-sized pieces, soft pureed food
- Moisten food with gravy or sauces
- Patients prefer soft and cool foods
- Supplements such as Ensure may be helpful, especially for elderly who prefer sweet foods

Asthenia or Neuromuscular Disorders

Safety Precautions

Eating

- Encourage small sips to clear mouth
- Remind patients to chew thoroughly
- Meal may take 30–45 minutes

Post-Meal Precaution

- Reduce risk of reflux by encouraging upright position for 15–30 minutes after eating

Dentures

Hygiene

- Assist patient with cleaning and use

Proper Fit

- May need adhesive
- May need to be refitted or replaced

Personal Preference

- Some patients prefer to wear dentures
- Others choose to stop wearing

Oral Hygiene

Cleanliness

- Encourage and assist with brushing and flossing 2–3 times day

Preventing Infection

- Antibiotics for periodontal disease

Dental Intervention

- Dental work or extraction if indicated
- Fluoride treatment as needed in special cases

Taste Disorders

Treat Underlying Disorder

- Sinusitis or other infections
- Gastric reflux
- Excessive sputum

Treat Symptom of Bad Taste

- Supplements, especially zinc, may provide relief
- Review medications that may taste bad

Dry Mouth

from Radiation

Medical Treatment

- Saliva substitute every 1–2 hours
- Pilocarpine 5mg q8 hours

  Rarely used

  May cause diarrhea or problems with secretions

Other Interventions

- Usually frequent sips of water sufficient
- Sipper cup or sports bottle easier for patient than straws

Dry Mouth

from Medication

- Seek to avoid side effect of dry mouth
- Substitute drug if possible

  Trazedone instead of amitriptyline for insomnia

- Reduce dosage if possible

Dry Mouth

in Last Hours of Life

- Increase liquids by mouth

  Ice chips

  Popsicles

  Flavored ices

- Mouth care may be more effective and can involve family in care

  Assisted sips

  Moistened sponge stick

  Lip balm

  Antifungal creams for celosis

Oral Candidiasis (Thrush)

Assessment

- Always suspect this infection as cause of problems with eating

Treatment

- Nystatin suspension swish and swallow
- Fluconazole (Diflucan)

  100mg daily for 10–14 days

  More expensive

  Easier and more quickly effective

Viral Infections: Cold Sores

Etiology

- Usually caused by herpetic infection

Treatment

- Consider Acylovir (Zovirax)
- Consider other antiviral treatment in cases of resistance and other special factors

Reflux Esophagitis
Practical Considerations

- Small meals
- Keep patient upright after meals

Medical management

- May need prokinetic such as metoclopromide
- Manage constipation
- H2 blockers
- Proton pump inhibitors

Mucositis
Oral Lavage with Soda Water

Procedure

- Baking soda (sodium bicarbonate)

  15 grams to a liter of water
- Swish and spit
- Keep at bedside for patient to use as needed

Advantage

- Helps cleanse mouth of dead tissue and debris
- Does not burn

Mucositis
Magic/Miracle Mouthwash

- Consult pharmacy about preparation

  Combination of medications

  May contain diphenhydramine, viscous xylocaine, Maalox, nystatin, tetracycline
- Order bottle to bedside for use by patient as needed
- Alternate with soda-wash rinse

Mucositis
Viscous Xylocaine

Dosage

- 2% 5ml every 4 hours as needed

Preparation

- Flavor or dilute to lessen its bad taste

Timing

- Sometimes used before meals
- May make it harder to swallow—changes sensation in mouth

Mucositis
Overview

- A somatic type of pain
- Opioid therapy

  Patients can usually benefit and respond

  May need to give opioid parentrally in severe cases
- Indications for Thalidomide 200mg daily

  Severe mucosal damage

  Ulceration not responding to other treatments

  Drug of last choice (may wish to consult first)

Difficulty with Eating

Prevalence

- Common in patients

Suffering

- Causes significant distress

Etiology

- Often multifactorial

Hope

- Careful and thoughtful evaluation can relieve suffering, improve Quality of Life, and increase oral intake

Selected Readings

Nutrition and Hydration: A Sociological Analysis

McInerney, F. "Provision of Food and Fluids in Terminal Care: A Sociological Analysis." *Social Science and Medicine* 34: 1271–1276.

Prevention of Tube Feeding

Volicer, L. "Strategies for Prevention of Tube Feeding in Advanced Dementia." *Quarterly Newsletter of the American Academy of Hospice and Palliative Medicine* 1 (2001): 16–18.

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1.8 Hydration

Key Points

1. Appetite and oral intake usually decline in the final days of life to a few sips or bites. Goals of hydration are to maintain function, improve Quality of Life, improve delirium, help satisfy sense of thirst and hunger, and engage family and friends in care.

2. Signs and symptoms of dehydration are more important than lab tests.

3. Benefits of <u>oral hydration</u> include low technology, minimal risk, ease of home use, fostering of human contact and pleasure, and low risk of causing fluid overload.

   Foster hydration with pleasant liquids, drinking aids and companionship/assistance at meals. Replete electrolytes naturally with sports drinks and tomato-based juices; hydrate naturally with sips of fluid. Two tablespoons of fluid four times in an hour equals 120ml of fluid. An IV at the rate of 75cc/hr takes 5 hours to infuse fluids equivalent to a canned drink (355 ml).

4. The burdens of <u>enteral feeding (NG/PEG)</u> usually outweigh the benefits.

   NG/PEG tube feeding at Life's End causes the discomfort of invasive procedures and restraints and the risk of aspiration, infections, nausea, diarrhea, distention, edema, and pulmonary congestion.

5. <u>Hypodermoclysis</u> offers a simple technique of administration of subcutaneous fluids, but policies and staff training in most clinical settings do not support its use.

   Burdens include possibility of dislodging needle, necessity of restraints, pain and swelling at site, risk of fluid overload, and cost of treatment.

6. <u>Parenteral intravenous administration</u> of fluids can be difficult and painful. Its use risks infections, restraints and fluid overload and creates a barrier to home care.

7. Key considerations in palliative hydration include evaluating burdens and benefits in the context of Goals of Care, seeking reversible cause, trying oral route, and observing for safety if an invasive route is indicated as a bridge to oral hydration.

Hydration

The Palliative Response

Goals of Hydration

- Help maintain function
- Improve Quality of Life
- May improve delirium
- Help satisfy subjective sensation of thirst and hunger
- Engage family and friends in care

Appetite and Oral Intake
at Life's End

- Status

  Declines in most patients

  People may take only few sips or bites in last days of life

- Typical Clinical Response

  Most hospital and nursing home patients have feeding tubes and/or IV's at time of death

Indications for Hydration

- Reversible Process
  (e.g., constipation)
- Treatable Infection
  (e.g., thrush)
- Temporary Insult

Burdens
Enteral and Perenteral Fluids

- Invasive procedures
- Pain and distress
- Edema and pulmonary congestion
- Provide little comfort
- Burden adds to suffering
- Burden often outweighs benefit

Diagnostic and Treatment
Considerations

Diagnosis

- Signs and symptoms more important than lab tests

  Skin tenting

  Concentrated urine with decline in output

  Postural symptoms

  Dry mouth

Treatment

- Look for reversible causes of decline
- Easier to manage early than late
- Consider appetite stimulant

Complication

Enteral and Parenteral Fluids

- Edema (third-spacing of fluids)

  Indicates intravascular fluid depletion rather than pure dehydration

  Often worsened by E/P fluids

- Often worsen pulmonary congestion

- Often lead to dyspnea without other benefits

Typical Concerns

Patients and Caregivers

- Dependence on others to be fed
- Loss of appetite
- Weight loss
- Loss of food as symbol of love

Fostering Patient Control

Some persons refuse food or fluid as way of having control.

- Foster control and good decisions by providing accurate information
- Provide patient-directed diet
- Feature foods easily swallowed/ digested

Dehydration

- Items for dry mouth and sense of thirst

  Ice chips

  Ice cream, puddings

  Frozen popsicles

- Drinking aids

  Sipper cups, wide grips

  "Thick-it" for fluids assists with swallowing

- Companionship and assistance at meals

Ideas for Oral Hydration

- Replete electrolytes

  Sports drinks

  Tomato-based juices for sodium

- Hydrate with sips

  Two tablespoons of fluid four times in an hour equals 120ml of fluid

  Encourage families to offer sips with each TV commercial

  An IV at rate of 75cc/hr takes 5 hours to infuse fluids equivalent to a canned drink (355ml)

Oral Hydration

Benefit Review

- Low technology
- Minimal risk
- Effectively administered at home
- Encourages human contact
- Can be pleasurable for patient
- Less risk of causing fluid overload

Enteral (NG/PEG)

Tube-Feeding at Life's End

- No evidence of benefit

  Causes patient discomfort

  Increases use of restraints

- Sometimes Goals of Care dictate a trial

  (e.g., patient with esophageal cancer and PEG tube undergoing palliative radiation to resolve esophageal obstruction)

Ask: Is tube-feeding a bridge to resuming oral intake?

Enteral Feedings

Benefits

- Increase mental alertness
- Reduce family anxiety
- Potentially prolong life for special event

Burdens

- Risk of aspiration
- Potential for infections
- Diarrhea and distention
- Nausea
- Invasive procedures
- Restraints

Hypodermoclysis

Subcutaneous Fluids

(30–50cc/hr of D5 ½ normal saline)

Advantages

- Simple technology for home use

Disadvantages

- Hospitals/nursing homes often not prepared
- Needle may still come dislodged
- Pain and swelling at site
- Some risk of fluid overload
- May still need restraints
- Cost of treatment

Ask: Is this a bridge to resuming oral intake?

Parenteral Feeding

Intravenous Fluids

Disadvantages

- Invasive
- Can be difficult and painful to insert IV
- Risk of infections
- Use of restraints
- Risk of fluid overload
- Sometimes seen as barrier to home care

Parenteral Intravenous Fluids

Considerations

- Goals of Care

  Is this a bridge to resuming oral intake?

- Consider time trial (2 liters over 8 hours)

  Stop IV fluids if not helpful

  Parenteral fluids may blunt thirst and hunger

  Some patients resume oral intake when fluids discontinued

- Avoid KVO fluids

Hydration

The Palliative Response

- Try the oral route
- Seek reversible cause of decreased oral intake
- Balance burden against benefit of perenteral and enteral hydration
- Consider Goals of Care
- If using a more invasive route

  Consider a time trial

  Observe carefully to maintain safety and prevent iatrogenic harm

Selected Readings

Nutrition and Hydration: Appropriate Use

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Nutrition and Hydration: A Sociological Analysis

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Treatment of Common Oral Conditions

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1.9 Intestinal Obstruction

Key Points

1. Intestinal obstruction is associated with ovarian and colorectal cancers (often a late manifestation) and is common with abdominal and pelvic primary tumors.

   Obstruction may be partial or complete, intermittent or persistent, have single versus multiple sites, and present in the small or large bowel.

2. Surgery is the best palliative treatment if possible.

   Co-morbid illness or progression of disease may make non-surgical management preferable.

3. Goals of Care in managing intestinal obstructions are relief of pain, nausea, and vomiting; avoidance of NG tube; and support of patient and family in an emotionally charged situation.

   Situation is charged because of patient's inability to eat and imminent death often within a few days to no more than a few weeks.

4. Consider subcutaneous, sublingual, topical, intravenous, or rectal routes for administration of medication. Oral route is not reliable.

   Usually choose morphine for pain control. Use sublingual or subcutaneous route, titrate dose to comfort, use small and frequent dosing schedule, or use pump with both continuous and PCA.

5. Octreotide puts the intestines at rest.

   Stops peristalsis against site of obstruction, reduces gastric secretions, increases electrolyte and fluid re-absorption, and often substantially reduces nausea and vomiting.

6. Antiemetics may be helpful. Patient may still vomit several times a day, but most prefer this to NG tube placement.

   Antiemetics include dopamine antagonist, haloperidol 1 SQ q6 (less sedating), chlorpromazine 25mg q6 PR (more sedating, less acceptable), and Lorazepam 1–2mg SQ q6 (if patient is anxious and sedation is welcomed).

7. Most patients will moderate oral intake on their own. It is not necessary to make patients completely NPO. Offer ice chips, sherbet, or juice.

Intestinal Obstruction

The Palliative Response

Diagnostic Considerations

- Etiology

  Ovarian cancer— late manifestation

  Colorectal cancers—late manifestation

  Abdominal tumors

  Pelvic primary tumors

- Distinctions

  Partial versus complete

  Intermittent versus persistent

  Single versus multiple sites

  Small versus large bowel

Management

- Surgical

  Best palliative treatment, if possible

  Not possible in some patients

- Nonsurgical

  Co-morbid illness may make it preferable

  Progression of disease may make it preferable

Good Prognostic Factors for Surgery

- Large-bowel obstruction treated with diverting colostomy
- Single site of obstruction
- Absence of ascites
- Good preoperative performance status

Poor Prognostic Factors for Surgery

- Proximal gastric obstruction or SBO
- Ascites
- Multiple sites of obstruction
- Diffuse peritoneal carcinomatosis
- Previous surgery and radiation treatment
- Poor performance and nutritional status
- Significant distant metastatic disease

Placing Stents by Endoscopy

- Esophageal obstruction
- Rectal obstruction
- Less effective in other sites
- Sometimes well tolerated but can lead to perforation, obstruction, and pain
- Usually only a temporary solution

NG or Venting Gastrostomy

- Most helpful in more proximal obstruction
- Decompresses the stomach but NG tube not tolerated long-term
- Venting gastrostomy may be more acceptable for longer term
- Rarely used due to generally poor condition of patients

Goals of Care

- Relief of pain
- Relief of nausea and vomiting
- Avoidance of the NG tube
- Support of patient and family as unit
  Emotionally charged situation
  Inability to eat
  Imminent death, often within a few days to few weeks

Route of Medication

- Oral route not reliable
- Alternatives to oral route
  Subcutaneous
  Sublingual
  Topical
  Intravenous
  Rectal

Pain Management

Usually morphine

- Sublingual or subcutaneous route
- Titrate dose to comfort
- Usually best to use small, frequent dosing schedule
- Pumps with both continuous and PCA are often best choice

Dexamethasone

40mg IV QD for 4 days

- Consider in most patients
- May result in reduction of edema around the site of obstruction and in temporary relief of obstruction
- May enable to resume oral medications including dexamethosone
- If not effective, can discontinue

Octreotide

0.1–2mg SQ q8 hours

- Puts bowel to rest and stops peristalsis against site of obstruction
- Reduces gastric secretions
- Increases electrolyte and fluid re-absorption
- Often substantially reduces nausea and vomiting

Antisecretory Drugs

- Reduce saliva and secretions
  - *Produce up to 2 liters a day*
  - *If obstructed, patient must vomit back up*
- Scopolamine topically
- Glycopyrrolate 0.1–2mg SQ q8 hours
- H2 blockade or proton-pump inhibitors
  - *May reduce gastric acid secretions*

Antiemetics

- Metocholopramide (Reglan)
  - *A prokinetic—not appropriate if obstruction complete*
  - *May be helpful in partial obstruction*
  - *Time trial—stop if colic worsens*
- Dopamine antagonist
  - *Haloperidol 1 SQ q6 is less sedating*
  - *Chlopromazine 25mg q6 PR is more sedating (less acceptable)*
- Lorazepam 1–2mg SQ q6
  - *If patient is anxious and sedation is welcomed*

Medical Management

- Outcome
  - *These regimens relieve symptoms satisfactorily in most patients*
  - *Patient may still vomit several times a day but usually prefers this to NG tube placement*
- Oral Intake
  - *Offer ice chips, sherbet, or juice*
  - *Most patients will moderate oral intake*
  - *Not necessary or kind to make completely NPO*

Total Parenteral Nutrition (TPN)

- Usually not recommended
- May have deleterious effects
- Problems with infections
- Very select patient population may benefit

Hydration

- Assess burden versus benefit
  - *Appropriate only for selected patients*
  - *May be difficult to maintain IV site*
  - *Problems with fluid overload*
- Hypodermoclysis
  - *Hydration via the subcutaneous route*
  - *May be helpful in selected patients*

Management

- Selection of treatment
  - *No comparative studies to determine best treatment in management of obstruction*
- Assess benefit and burden daily
- Adjust medication
  - *Maximize control of symptoms*
  - *Support patient and family*

Selected Readings

Overview

Muir, J. C. “Malignant Bowel Obstruction.” In *Principles and Practice of Supportive Oncology* edited by A. M. Berger, R. K. Portenoy, and D. E. Weissman. New York: Lipincott Williams & Wilkins Healthcare 2 (1999): 1–7.

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2.1 Access to Medical Care: Medical Insurance and Suffering at Life's End

Key Points

1. Medical insurance or the lack thereof has a major impact on the type of medical care a patient may receive.

   Insurance coverage, rather than patient or family preference, often determines location of care.

2. Many families deplete their savings caring for loved ones at the end-of-life.

   Terminal illness impoverishes 40% of patients and families. Many patients worry about being a financial burden on their families.

3. Private insurance is often contingent on employment. Persons who become ill and unable to work often lose insurance coverage. Private insurance frequently does not cover hospice or home care.

   Payment schedules and covered services vary greatly from policy to policy. Patients who are unable to pay insurance premiums due to illness and loss of income lose their coverage.

4. Medicaid is a federal program administered by the state.

   Patients must apply for Social Security disability to apply for Medicaid.

5. Honorably discharged veterans are eligible for medical services through the Veterans Administration.

   Services and co-payment may vary based on factors such as income and service-connection status.

6. The Medicare hospice benefit covers hospice care.

   A physician certifies an individual as eligible for hospice care based on criteria that reflect the severity of the illness, primarily limited life expectancy. Patients or their representatives sign a form to elect hospice care that is primarily symptom focused and supportive and usually delivered in the home or a nursing home setting.

Access to Medical Care at Life's End

The Palliative Response

Impact of Medical Insurance

- Coverage, or lack thereof, determines

  Type of medical care a patient may receive

  Location of care

- Patients often use several different sources of payment during the course of an illness

Impact of Life's End on Family Finances

- Expenses not covered by insurance
- Loss of income
- Loss of insurance
- Loss of savings
- Loss of assets

Financial Burden

Many additional expenses at Life's End are not covered by insurance

- Transportation
- Medications
- Durable medical supplies
- Nondurable medical supplies
- Co-payments

Loss of Income

- Patient loses job and income due to inability to work
- Family members must leave work or limit hours to care for patient

Loss of Insurance

- Patient loses insurance when unable to maintain employment
- Patient is unable to pay COBRA

  The Consolidated Omnibus Budget Reconciliation Act of 1985 is a law that allows individuals to maintain their insurance if they leave their job. Most are unable to afford the cost if unemployed.

Loss of Savings

- Many families deplete their savings while caring for loved ones at Life's End

Loss of Assets

- Patient often loses home or other assets to qualify for long-term care

Impoverishment

- Terminal illness impoverishes 40% of patients and families

Emotional Burden

- Many patients worry about being a burden on family finances

Forms of Medical Insurance

Medicare

- Part A
- Part B
- Purchase supplements for co-pay
- Medicare HMO

Medicare Hospice
Benefit

- Type of care
  - *Primarily symptom management*
  - *Usually delivered in home or nursing home*
- Eligibility
  - *Must have Medicare A*
  - *Physician certifies person as terminally ill and eligible for hospice care*
  - *Patient elects hospice care*
    - *Certifies understanding of terminal status*
    - *Requests care as defined by hospice*

Medicaid

- Administration
  - *Federal program administered by each state*
  - *Differs from state to state*
  - *Funds are a State-Federal match*
- Eligibility
  - *Must first apply for Social Security Disability*
- Primarily covers (e.g., Alabama)
  - *Nursing home care*
  - *Prenatal and obstetrics care*
  - *Pediatric care for children without private insurance*

Veterans Administration

- Eligibility
  - *Honorably discharged veterans*
- Coverage
  - *Services and co-payment may vary*
- Factors determining coverage
  - *Income*
  - *Service-connection status*

Private Insurance

- Policies vary greatly
  - *Payment schedules*
  - *Covered services*
- Limitations for care at Life's End
  - *Hospice or home care frequently not covered*
  - *Patient must continue to pay premiums to maintain coverage*

Medically Indigent

Example: Jefferson Health System

- Eligibility
  - *Medically indigent resident of Jefferson County*
- Coverage
  - *Primary ambulatory and acute hospital care*
  - *Some prescriptions*
  - *Some durable medical supplies*
  - *HOSPICE CARE through County Health Department*
- Co-pay determination
  - *Income*
  - *Size of household*

Access to Medical Care
The Palliative Response

- Be aware of realities of healthcare financing
- Be informed about resources available for patients
- Be sensitive to the economic burdens and realities of a life-threatening illness on patients and their families

Case 1

When Charlie was 40 years old, he began to have severe pain in his left hip that prevented him from working as a construction laborer. Thinking that he had injured himself on the job, he went to see a doctor to explore a worker's compensation claim.

The x-rays revealed that Charlie's problems were much more serious than first believed. He was referred to the oncology clinic, where it was discovered that he had metastatic cancer to the bones from an asymptotic lung cancer in his left lung.

Charlie was informed that:

1. the cancer was incurable because it had spread beyond the lung;
2. his life expectancy was estimated at less than a year (and that patients rarely live more than two years);
3. he would never be able to work again; and
4. he needed to start radiation treatment to reduce the pain in his hip and the risk of fracture, a treatment that would cost approximately $10,000.

Charlie is married with three young children. His employer offered no health insurance benefits.

What would you do?

Options

- Apply for Social Security Disability
  Charlie could wait 3–6 months for a determination.

- Apply for Medicare
  Since Charlie is only 40 years old, he must wait for two years after being deemed disable to apply for Medicare.

- Apply for Medicaid
  Charlie must apply for disability first.

- Apply for Assistance from Local Charities
  Such assistance is usually limited to a one-time benefit of a few hundred dollars.

Charlie is sponsored for the radiation by the local charity hospital. His pain improves, but within three months he develops progressive disease.

Charlie is a candidate for a chemotherapy study for a new experimental drug being compared to standard chemotherapy. Chemotherapy would cost more than $1000 a month. He enrolls in the study, which provides free chemotherapy. One month later, Social Security Disability and Medicaid are granted. Six months later, the lung cancer is stable but the chemotherapy study is completed.

One year after the initial diagnosis, several brain metastases are discovered, and Charlie begins another course of radiation therapy. Charlie enrolls in a hospice program using his Medicaid benefit. Charlie dies 20 months after the original diagnosis and four months before his Medicare benefits were to begin.

Questions

- What are the problems that Charlie had in accessing medical care?

- What are some possible changes in our health-care funding and delivery systems that would have improved Charlie's access to care and the quality of his care?

Case 2

Brenda, a 35-year-old self-employed cosmetics saleswoman, noticed that she had acquired a pot belly and that, over the last few weeks, she had developed small red spots on her legs. She decided to stop in at a local walk-in emergent care clinic between sales calls. She was told that her platelet count was dangerously low, which might cause her to bleed. Since she had no private insurance, she was referred to the local charity hospital.

Brenda was diagnosed with advanced cirrhosis of the liver brought on by an asymptotic infection with the hepatitis C virus and worsened by daily consumption of 2–3 alcoholic drinks. Further evaluation revealed ascites and an enlarged spleen causing the low platelet count. Brenda also has enlarged veins in her esophagus, called varicies.

Brenda stops drinking any alcohol and begins taking medications to reduce the fluid collection and the chance of a bleeding episode from the varicies. Despite this, she is admitted to the intensive-care unit for a life-threatening bleeding episode that requires more than 8 units of blood.

Brenda and her husband are informed that:

1. the cirrhosis of the liver is irreversible and progressive;
2. only one-third of patients with a bleeding episode survive for one year;
3. a liver transplant might help her condition, but she must have some form of insurance and be abstinent from alcohol for one year before she can be evaluated.

What would you do?

Options

- Apply for Social Security disability
  Brenda could wait 3–6 months for a determination

- Apply for Medicare
  Since Brenda is only 35 years old, she must wait for two years after being deemed disabled to apply for Medicare.

- Apply for Medicaid
  Since Brenda's husband is employed and they have some assets, such as a home and a car of modest value, their income is above the minimum allowed to qualify for Medicaid.

Brenda was awarded Social Security disability three months after the original diagnosis. She has been abstinent for one year but has had two more life-threatening episodes of bleeding and has declining hepatic function. It will be 10 more months before she is eligible for Medicare.

Questions

- What are the problems Brenda had in accessing medical care?

- What are some possible changes in our health-care funding and delivery systems that would have improved Brenda's access to care and the quality of her care?

Case 3

Despite David'd weight of nearly 325 pounds, his family has managed to bring him to the ER for the third time this month. Each time he received a shot of IV medicine to make him urinate some of the nearly 30 pounds of water weight that had collected since the previous visit and was causing him to gasp for breath.

David had developed severe heart disease secondary to morbid obesity and emphysema from smoking. The ejection fraction of his heart was less than 20% (normal is 60%). David had been intubated in the past when he was severely short of breath and had informed his family and doctor that he wanted no aggressive life support in the future. In light of this and his frequent visits to the ER, David was referred to home hospice.

Having been disabled for more than two years, David qualified for Medicare; but it did not help pay for the expensive medicines required for his heart and lung conditions. The hospice team developed a plan to help David and his family to manage his illness. The plan included setting up David's medications in a pill box, helping the family budget for medicines not covered under the Medicare Hospice Benefit, and daily weighing to adjust David's water pill dose.

In the first month, David controlled his water weight gain, his depression and anxiety improved, the hospice dietician helped him lose nearly 15 pounds, and a low dose of opioid reduced his constant sense of breathlessness and improved his exercise tolerance. After six months with no ER visits, the hospice program discharged David since his prognosis seemed to have improved and was probably greater than the six months required for hospice care.

What would you do?

Outcome

The hospice program tried to prepare David and his family for discharge by establishing him with a primary doctor and seeking financial support for his medicines. David's new doctor did not approve of the use of the opioid (Lortab5™, 1 tablet four times a day) for air hunger, and David found it difficult to keep his clinic appointments.

Four months later, David had three episodes of severe shortness of breath requiring an ER visit. On the third occasion, he died in the ambulance and was coded unsuccessfully.

Questions

- What are the problems that David had in accessing medical care?

- What are some possible changes in our health-care funding and delivery systems that would have improved David's access to care and the quality of his care?

Medicare

Medicare is a national health insurance program for people ≥65 years of age, certain younger disabled people, and those with kidney failure on dialysis for greater than three months.

A U.S. citizen who is at least 65 years old is eligible for Medicare if the person or the person's spouse worked for at least ten years in Medicare-covered employment. A person under 65 can get Medicare if the person is a dialysis or kidney-transplant patient or has received Social Security disability benefits for 24 months.

Medicare is divided into Part A (Hospital Insurance) and Part B (Medical Insurance). Part A helps pay for care in a hospital, skilled nursing facility, home health and hospice care. Part B helps pay for physicians, outpatient care, and various other services not covered in Part A.

Medicare Hospice Benefit

Medicare coverage for hospice care is available only if:

1. the patient is eligible for Medicare Part A;
2. the patient's physician and hospice Medical Director certify that the patient is terminally ill with a life expectancy of six months or less;
3. the patient signs a statement choosing hospice care instead of standard medical benefits for the terminal illness; and
4. the patient receives care from a Medicare-approved hospice program.

When all requirements are met, Medicare covers physician services, nursing care, medical equipment and supplies, outpatient drugs for symptom relief and pain management, home health aides, physical and occupational therapy, speech therapy, and dietary and other counseling.

Not covered are treatment for terminal illness except for symptom management and/or pain control, care provided by another hospice not arranged by the patient's hospice, and duplication of required hospice services by another provider.

Social Security Disability

A person can receive Social Security (SS) disability benefits at any age. To qualify, a person must have contributed to Social Security long enough and recently enough through their employment. In most cases, a person needs 20 credits earned in the last ten years ending in the year of becoming disabled. However, younger persons may qualify with fewer credits:

- Before age 24 – Six credits earned in the three-year period ending when the disability began
- Age 24–31 – Must have credit for working half the time between age 21 and the time of becoming disabled
- Age 31 and up – Varies depending on the age disabled

Disability is determined by a team consisting of an MD and a Disability Evaluation Specialist. Disability is determined in a step-by-step process involving five questions:

1. Are you working? – A person earning greater than $500/month cannot be determined as disabled.
2. Is your condition severe? – The impairment must interfere with basic work-related activities for the claim to be considered.
3. Is the condition found in the list of disabling impairments? – Social Security maintains a list of major body impairments sufficiently severe to warrant automatic determination of disability. If the condition is not on the list, Social Security will determine whether it is severe enough to warrant disability.
4. Can the person do the same type of work previously performed? – If the condition is severe, but not the same or of equal severity as an impairment on the list, then Social Security must determine if it interferes with the person's ability to do the work performed in the last 15 years. If it does not, the claim can be denied.
5. Can you do any type of work?

Note: A person must receive Social Security disability for 24 months to be eligible for Medicare.

Medicaid

Generally, Medicaid is awarded if a person is eligible for Supplemental Security Income (SSI). Medicaid covers health-care costs for persons who are blind, disabled, or fall below a certain percentile of the poverty level. Unlike Medicare, Medicaid offers a perscription benefit. Most patients in nursing homes are covered by Medicaid after depleting their personal funds.

Private Insurance

Different policies pay different amounts. In general, private insurance does not pay as well as state and federal programs except in the case of Railroad Retirement, Champus, and certain pensions. Supplemental policies are almost always necessary to cover all expenses.

The Medically Indigent

Example: Jefferson County, Alabama

- Covered in Jefferson County through the Jefferson Health System.
- The patient must be a Jefferson County resident.
- The patient is assessed according to income and the number of persons in the family.
- A scale based on the federal poverty guidelines is used to determine the amount of assistance given.

Access to Medical Care at Life's End

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2.2 Medicare Hospice Benefit

Key Points

1. Hospice care, now available in most communities in the United States, offers palliative medical care and serves patients and families as a unit with emotional, social, and spiritual support.

2. Patients certified as terminally ill with a life expectancy of less than six months may elect to receive hospice care.

3. A multidisciplinary team collaborates with patient and family to provide hospice care.

4. Hospice services include medical equipment and supplies, medication for pain and symptom control, chemotherapy and radiation (if for palliation), grief counseling, and bereavement support.

5. Hospice benefits cover hospital services for short-term symptom control and temporary respite care to relieve family caregivers. They do not cover curative treatments or extensive evaluations inconsistent with the hospice approach.

   Medicare continues to cover treatment for conditions other than the terminal illness.

6. Patients, initially certified for two 90-day periods, may be re-certified for an unlimited number of 60-day periods if the condition is still terminal with life expectancy within six months.

7. Discharge from hospice occurs if prognosis improves or if patient wishes to seek curative treatment. Patient may be readmitted if becomes eligible due to declining health.

Medicare Hospice Benefit

The Palliative Response

History of Hospice Benefit

- 1983—Federal Government adds hospice benefit to Medicare Part A
  - *National benefit for Medicare-eligible patients*
  - *Developed by Center for Medicare and Medicaid Services (CMS) and Congress*
  - *Following successful demonstration project*
- Home hospice programs now available in most communities in USA

Support for Hospice Services

- Other sources
  - *Medicaid*
  - *VA*
  - *Private insurance*
  - *Charity care by the hospice itself*
- Accessibility
  - *All patients treated the same regardless of Medicare coverage*

What Is Hospice Care?

Palliative Care

- Medical support
- Emotional support
- Social support
- Spiritual support

Whom Does Hospice Serve?

- People with terminal illness
- Family unit of patient

Settings of Hospice Services

- Home
- Nursing home
- Hospice facility
- Hospital

Medicare Hospice Eligibility Process

- Patient eligibility
  - *Medicare Part A (Hospital Insurance)*
- Medical certification
  - *Terminal illness— < six months life expectancy*
  - *Hospice medical director and patient's physician*
- Patient election
  - *Patient elects hospice care over routine Medicare*
- Program eligibility
  - *Medicare-approved hospice program*

Prognostication Criteria

- Prognostication is often difficult
- Illness-specific criteria to support prognosis of less than six months

Certification requirement

- "Six-months rule" often discourages referral and shortens hospice time for eligible patients who could benefit from earlier referral
- No penalty for patient or physician if survival exceeds six months

Multidisciplinary Hospice Team

- Patient and family
- RNs, LPNs, Home health aides (nursing care)
- Social work
- Chaplain (pastoral care)
- Physician
- Trained volunteers
- Pysical/Occupational/Speech therapists, nutritionist

Types of Services Covered by Hospice

- Medical equipment and supplies
- Medication for pain and symptom control
- Professional services of multidisciplinary team
- Clinical services

Hospice Clinical Services

- Treatment that is palliative in nature (e.g., palliative chemotherapy and radiation)
- Counseling and bereavement services for family for up to one year after death

Hospital Services Covered by Hospice

- Symptom control
  - *Short-term inpatient care if symptoms not controlled at home*
- Respite care
  - *Provides temporary relief to family or primary caregiver*
  - *Up to five days*

Types of Services Not Covered by Hospice

- Treatment to cure a terminal illness
- Extensive evaluations not consistent with hospice approach

  Focus is comfort, support, and symptom management

Medicare Coverage

Other Conditions

- Medicare continues to cover care and treatment for conditions other than the terminal illness

  Example: 66-year-old man with CRF on dialysis develops metastatic lung cancer
- Medicare hospice benefit covers admission to hospice for lung cancer
- Medicare A continues to cover dialysis

Co-Payments

- Medicare A and B

  80% of charges/ 20% co-payment
- Medicare hospice

  Medicare per diem reimbursement to hospice

  No co-pay for hospice

  May be a 5% co-pay for inpatient respite care
- Medications

  Patients responsible for medications not related to diagnosis

  May be a $5 co-pay for some prescriptions

Time Limit

- Certification

  Patient initially certified for two 90-day periods

  Certified thereafter for an unlimited number of 60-day periods
- Re-certification

  Medical director and physician review status

  Certify that prognosis is still terminal

  Certify that it is probable that the patient will die within the next six months

Hospice Discharge

- Patient becomes ineligible

  Remission

  Significant improvement

  No penalty for discharge

  Patient may be readmitted if becomes eligible due to declining health
- Patient elects discharge

  Some patients choose to be discharged to seek "curative" care not provided by hospice

Medicare Hospice Benefit

A Palliative Response

Hospice care is the ideal palliative response for many terminally ill patients and their families.

Refer early for maximum benefit.

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2.3 Nursing-Home Care

Key Points

1. Nursing-home care provides room and board; 24 hours/day assistance with Activities of Daily Living (ADL); and psychosocial, physical, and occupational therapies.
2. Factors leading to nursing home placement include inability to perform ADL, incontinence, functional impairment, cognitive impairment, and lack of social support system.
3. Medicare Part A covers care by a skilled nursing facility (SNF), hospice, or home health. Medicare reimbursement is 100% for 20 days ($100 co-pay for days 21–100).
4. Medicare Part B covers physician services, lab work, x-rays, and outpatient physical, occupational, and speech therapy (PT, OT, ST).
5. Medicaid, the payer of last resort, is a joint federal and state program that reimburses for custodial care (room and board) and medications for impoverished persons (income < $1500/month) in SNF.
6. Transfer summaries for admissions to SNF from hospital should include discharge diagnoses, most recent labs, procedures, study results, and Next of Kin (NOK)/Surrogate/Power of Attorney (POA).
7. Nursing-home orders should avoid:
    - PRN Orders—Medications should be scheduled
    - Open-ended orders—Use stop dates
    - Inappropriate PT/OT/ST consults—e.g., severe dementia
    - Restrictive Diets—#1 cause of weight loss in nursing homes
    - Patterned Blood Sugars
    - "Consult GI for PEG placement"—Understand the goals of the patient and family; it is not "nursing-home policy" to tube-feed patients who cannot take PO
    - Discharging with Foley Catheter, with certain exceptions
8. Ensure that each medication prescribed is indicated and has a corresponding diagnosis. Start low and go slow. Order as BID/TID etc., instead of qXhrs. Follow federal prescribing guidelines of Beer's List.

Nursing-Home Care

The Palliative Response

Levels of Long-Term Care

- Retirement communities
- Assisted living
- Skilled nursing facilities (SNF)

Nursing-Home Care

- 24 hr/day nursing care
- Assistance with Activities of Daily Living (ADL)

  Feeding, bathing, toileting, dressing
- Psychosocial, physical, occupational therapy
- Room and board

Factors Affecting Nursing-Home Placement

- Inability to perform ADL

  Incontinence is primary reason for nursing-home admission
- Functional impairment
- Cognitive impairment
- Lack of social support system

Medicare and Medicaid

Medicare Part A Coverage

- Skilled nursing facility
- Hospice
- Home health
- Dialysis
- 100% reimbursement for 20 days ($100 co-pay for days 21–100)

Medicare and Medicaid

Medicare Part B Coverage

- Physician services
- Lab
- X-ray
- “Outpatient” PT/OT/ST
- Must elect to pay in

Medicare and Medicaid
Medicaid Coverage

- Custodial care (room and board) in SNF
- Medications
- The payer of last resort
- Joint federal and state program
- Reimbursement varies from state to state

Medicaid Eligibility

- Impoverished (Income < $1500/month)
- Spend-down to qualify

  Exemptions: automobile, life insurance, personal effects < $4000, real property in certain classes
- Look back 36 months for assets transferred as gifts, etc.
- Formula: Assets/Mo. NH Cost = Period Ineligible

Admissions to SNF

- From home
- From hospital with transfer summary

  D/C diagnoses

  Most recent labs

  Procedures

  Results studies

  NOK/Surrogate/POA

  Code status

  Candidate for rehab? If no, why not?
    - *Goals*
    - *Potential*

Skilled Nursing Facility
Skills of Care Available

- Feeding tubes
- Fractures
- IVs, IMs
- Ostomy care
- Wound care
- Physical therapy
- Occupational therapy
- Speech therapy

Orders to Avoid

- PRNs

  If a medication is needed, it should be scheduled (e.g., analgesics)
- Open-ended orders

  Use stop dates (e.g., antibiotics, opthalmic preparations, dermatologic preparations)
- Inappropriate PT/OT/ST consults

  (e.g., Severe dementia—unable to learn, recall)

Avoid Restrictive Diets

- #1 cause of weight loss in NH
- Have no place in NH setting; residents should be able to eat anything they can
- Remember to specify consistency
- Request “spoonfeed” or “assist with feeding”
- Exception—short-stay rehab for otherwise functional patient

Avoid Patterned Blood Sugars

- In stable Type 2s
- If unstable for finite period (three days, one week) with insulin titration per nursing-home physician

Avoid "Consult GI for PEG Placement"

- Understand the goals of the patient and family
- It is not "nursing-home policy" to tube-feed patients who cannot take PO

Avoid Discharging with Foley Catheter

Exceptions

- For wound healing

  "d/c Foley when wound healed"
- Hip, LE fracture

  "d/c Foley when fracture healed"
- Neurogenic bladder

Prescribing Drugs in NH

- Ensure it is indicated

  Each drug prescribed needs a corresponding diagnosis
- "Start low and go slow"
- Prescribe low-cost equivalents when possible
- Order as BID/TID, etc., instead of qXhrs

The Beer's List

- Delineates prescribing practices in NH
- Adopted as federal guideline on prescribing
- Used by state surveyors in evaluating drug prescribing in NH
- Does not prohibit the prescribing of drugs but requires physician documentation on the use of certain drugs, effectively proscribing their use

Examples of Beer's List

Drug	*Strength*	*Dosing Schedule*
FeSO4	*325mg QD*	*GI side effects, limited indications (blood loss)*
Dig	*0.0125mg QD*	*Renal impairment, risk of toxicity*
Propoxiphene	*Don't prescribe*	*Limited efficacy, toxic metabolites in renal insufficiency*
Benzodiazepine	*Any*	*Don't prescribe unless willing to give a legitimate psychiatric diagnosis*
Tricyclics	*Any*	*Don't prescribe unless there is no other drug for sleep, neuropathy, or depression*
Antipsychotic	*Any*	*Don't prescribe unless documented psychiatric diagnosis, dementia w/agitation, hospice (N/V)*

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2.4 Ethical Considerations

Key Points

1. The primary ethical principles in Palliative Care are autonomy, beneficence, non-maleficence, justice, and informed consent.

2. Ethical principles can sometimes conflict with each other.

   Unlimited or unguided patient autonomy can conflict with beneficence, non-maleficence and justice.

3. An action is ethical if its intent is beneficent even if outcome is negative.

   Double effect is the recognition that any action taken on behalf of the patient can have multiple impacts, both positive and negative. Thus, if taken to its logical conclusion, the principle "First of All, Do No Harm" would paralyze physicians.

4. Use of opioid medications for relief of pain or dyspnea is accepted and expected as standard pain and symptom management.

   The medical system too often under treats pain; providers have recently faced criminal prosecution for under treatment of pain in terminally ill patients.

5. Forgoing life-sustaining treatment applies to a number of interventions beyond ventilator support.

   The decision to withdraw or not begin a therapy includes such interventions as CPR, dialysis, tube feeding and medications as well as ventilator support.

6. The purpose of intentional/terminal sedation is symptom-relief, not death (double effect).

   Intentional sedation seeks to provide relief from severe, unrelenting physical symptoms that are irreversible and unresponsive to maximal symptom control.

Ethical Considerations

The Palliative Response

The Ethical Principle of Autonomy

Patient Choice

Self-determination in decisions regarding accepting or refusing specific treatment.

The Ethical Principle of Beneficence

Do Good

Working out together what would be in the best interest of a patient.

The Ethical Principle of Non-Maleficence

Minimize Harm

Protection of patients from injury and iatrogenic harm.

Includes wise counseling as a component of informed consent.

The Ethical Principle of Justice

Fair use of available resources for health care

Conflict of Autonomy with Other Principles

- In the recent history of medicine, autonomy often has been considered the most important of the ethical principles
- Unlimited or unguided patient autonomy can conflict with the ethical principles of beneficence, nonmaleficence, and justice

The Ethical Principle of Informed Consent

Voluntary and informed agreement to specific treatment or plan of care

Capacity

The presence of sufficient mental capacity to exercise autonomy and to give consent

Beneficence and Double Effect

- Any action taken on the behalf of a patient has potential for multiple impacts, positive and negative, on a patient's well-being
- An action is ethical if its intent is beneficent even if a negative outcome should occur

Limiting Considerations

First of All, Do No Harm

If carried to its logical conclusion, this principle would prevent physicians from participating in any patient-care decisions; since any action, however harmless it may appear, could have negative consequences for an individual patient

Exercise in Ethical Decision-Making

Six different scenarios will be described regarding care at Life's End. As a group you will fill out a table regarding:

- Certainty of death
- Requirement for patient competence
- Physician involvement in the interventions
- Legal status of the intervention
- Ethical consensus

Interventions

Standard Pain Management

- Use of opioid medications for the relief of pain or dyspnea is accepted and expected
- Intent is control of pain or other symptoms
- Medical system too often under-treats pain
- Some providers have faced criminal actions for inadequate pain control for terminally ill patients

Foregoing Life-Sustaining Therapy

- Discussions often limited to ventilator support
- Includes a number of interventions beyond ventilator support
  - *CPR*
  - *Dialysis*
  - *Tube feeding*
  - *Medications*
- Includes withdrawing a therapy or making a proactive decision not to begin a treatment

Voluntary Cessation of Eating and Drinking

- A rare event requiring sustained will power
- Some may consider this suicide
- Evaluation of depression and capacity are appropriate

Intentional/Terminal Sedation

- May be indicated for severe unrelenting physical pain or other distressing symptoms, such as delirium or dyspnea, which are not reversible and not responding to maximal symptom control
- Patient is sedated—usually with a combination of opioids, benzodiazepines and haloperidol—because sleeping provides respite from the symptoms
- Purpose of the treatment is relief of symptoms, not death (double effect)

Physician-Assisted Suicide

Oregon Regulations

Physician provides the means for patient to take his/her own life

- Patient must make request in writing
- Waiting period
- Second physician must certify illness as terminal
- May be a psychiatric evaluation
- Patient fills prescription for barbiturate to use at his/her discretion
- Patient must take the medication unaided by staff or family

Voluntary Active Euthanasia

Physician, upon patient request, administers lethal medication by injection or oral route

- Patient must be competent
- Illegal and likely to be prosecuted
- Limited and controversial support for this practice

The Ethical Principle of Beneficence

Do Good

While all the ethical principles are important, working with the patient/family toward <u>beneficence</u> often, in the end, will achieve the other principles.

Intervention	Certainty of Death	Patient Competence	Physician Involvement	Legal Status	Ethical Consensus
Standard pain management					
Foregoing life-sustaining therapy					
Voluntarily stopping eating and drinking					
Terminal sedation: heavy sedation to escape pain, shortness of breath, other severe symptoms					
Physician-assisted suicide					
Voluntary active euthanasia					

Selected Readings

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2.5 Physician-Assisted Suicide

Key Points

1. Physician-assisted suicide (PAS) is legal only in Oregon.
   PROCEDURE: Applicants must be Oregon residents whom two physicians certify as terminally ill with a prognosis of less than six months. Applicant must request PAS in writing and undergo a waiting period during which a psychiatric evaluation may be requested. Patient receives barbiturate prescription that he must take <u>unaided</u> when and if he decides to do so.

2. Patients requesting PAS are usually attempting to control social and emotional, rather than physical, suffering.
   Palliative care can manage most physical suffering. Motivation for requesting PAS includes fear of dependency, lack of ability to care for self, and becoming a burden on others.

3. Respond to request for PAS by assessing effectiveness of palliative care and revising care plan to address patient concerns.
   Reevaluate patient's response to interventions, including treatment for depression over the course of the illness; PAS requests are usually not persistent over time.

4. Be open to discussing PAS with patients. Maintain therapeutic relationship with patient despite disagreement with PAS.
   Listen to patient's concerns, remain professional and calm and normalize patient's thoughts about PAS. Don't freak out! Continue to support patient and family and to seek other sources of support. Continue to reduce and relieve suffering at Life's End. Neither abandon nor judge the patient.

5. Prepare for patient-clinician interactions by developing expertise in dealing with dying.
   Expertise in dealing with the dying process includes ability to control symptoms, manage the entire course of terminal illness, handle emergencies or expected complications, and access community resources and the assistance of interdisciplinary team.

6. Intentional sedation, sometimes the only means of providing relief from intolerable suffering not controlled by aggressive symptom management, is <u>not</u> PAS or euthanasia. Its intention is the relief of suffering. The intention of PAS is the death of the patient.

Physician-Assisted Suicide

The Palliative Response

Physician-Assisted Suicide

Legal Only in Oregon

Eligibility

- Patient must be Oregon resident
- Two physicians must certify illness as terminal with prognosis of less than six months

Physician-Assisted Suicide

Initial procedure

- Must request PAS in writing
- Waiting period
- Psychiatric evaluation may be requested

PAS procedure

- Patient receives barbiturate prescription
- Patient decides when/if to use medication
- Patient must take medication <u>unaided</u>

The Experience in Oregon

Requests and use

- 50–75 patients per year formally request PAS
- About one third of those who obtain medication actually use it for PAS

The palliative alternative

- Oregon has a high utilization rate for hospice and palliative-care services—partially in response to the debate and the Death with Dignity Law

National Survey Data

PAS

Terminally-ill patients (988)

- 60% support PAS in hypothetical situations
- 10% had seriously considered PAS in their own situations

Primary-care physicians

- About 25% reported a request for PAS

Oncologists

- About 50% reported a request for PAS

Characteristics of Patients

Requesting PAS

- Anyone might think about PAS and hastened death in the context of a serious and life-threatening illness
- Those requesting PAS are more likely:

  Male

  White

  Higher level of education attainment

  Higher socioeconomic class

  Not active in a religious practice

Reasons for Seeking PAS

Emotional and social suffering

- Control

  Over the situation and terminal illness
- Fear

  Dependency

  Lack of ability to care for self

  Becoming a burden on others

Responding to Request

Attitudinal Guidelines

Be open to discuss PAS

- Listen to patient's concerns
- Remain professional and calm
- Normalize patient's thoughts about PAS

Don't Freak Out

When a Patient Asks about PAS

Clarify

- Patients commonly use unclear language secondary to concern about physician's response to request
- Ask in calm, supportive way for clarification about what assistance patient is seeking

When a Patient Asks about PAS

Explore reasons for request

- Fear of uncontrolled symptoms
- Fear of loss of "dignity" or control
- Burden on family
- Each patient may have unique reasons

When a Patient Asks about PAS

Assess effectiveness of palliative-care interventions

- Physical symptoms
- Social support
- Spiritual concerns
- Emotional aspects (especially depression)

When a Patient Asks about PAS

Revise the care plan

- Address and respond to patient concerns
- Reevaluate response to interventions over the course of the illness

  PAS requests are usually not persistent over time

Palliative Response to the Underlying Suffering

In response to a request for PAS:

- Assess and manage untreated depression
- Manage physical suffering

  Most can be managed such that patients have the capacity to bare the distress

Response to PAS Request

Summary

- Physician-assisted suicide is illegal and not condoned as an ethical practice
- Make explicit that physician-assisted suicide is not a clinical option

but

- Reassure patient and family that you and the interdisciplinary team will support them throughout the dying process

Response to PAS Request

Summary

Maintain therapeutic relationship

- Despite disagreement about PAS
- Continue to be a source of support and care for patient and family
- Neither abandon nor judge
- Continue to seek sources of support
- Continue to reduce and relieve suffering at Life's End

Preparation for Managing PAS Request

Expertise in dealing with dying process is the best preparation

- Expertise in symptom control
- Knowledge about the time course of illness
- Preparation for emergencies or expected complications
- Knowledge about community resources
- Ease in working with interdisciplinary team

Uncontrollable Symptoms

The Palliative Response

- Admission

  Inpatient palliative care or hospice unit
- Consultation
- Multidisciplinary care

  To manage symptoms across a broad spectrum of suffering

Uncontrollable Symptoms

The Palliative Response

Intentional sedation

- When aggressive symptom management does not control symptoms
- When only means of relieving distressing symptom is sedation to a sleeplike state
- Intention is relief from intolerable suffering

  Intention is not death

  Not considered PAS or euthanasia, in which intention is the death of the patient

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Overview of Issue

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3.1 Delirium

Key Points

1. Delirium is deadly.

   When people become delirious, they stop eating, drinking fluids, and taking medicines. They may injure themselves or be placed in restraints. The prognosis is grave if the delirium does not clear. The delirium complicates and interferes with treatment of other aspects of the illness and often results in the use of restraints.

2. Delirium is common.

   15–20% of people who are hospitalized may experience delirium, and 80–90% may have some delirium in the days and weeks before death.

3. Delirium causes extreme emotional suffering.

   A delirious individual is often frightened, agitated, and upset. Most important, the delirium interferes with meaningful personal interactions with family, friends, and professional staff at Life's End.

4. Delirium is treatable and in some cases reversible.

   The physician must individualize the treatment of delirium to maximize the patient's comfort and safety. The physician must temper the search for etiology and any corrective efforts with consideration of the burden of treatment on individuals at Life's End. In any case, treatment of the symptoms with neuroleptics (haloperidol) is usually appropriate.

5. Mistreatment with benzodiazepines (lorazepam) often exacerbates delirium.

   Health-care providers often misinterpret the agitation associated with delirium as anxiety and fear. Treatment with benzodiazepines (lorazepam) for agitation may lead to a vicious cycle of escalating doses that exacerbates the underlying delirium.

Delirium

The Palliative Response

A Definition

- Confusion
- Sudden onset
- Waxing and waning
- Disturbed level of consciousness
- Labile emotions
- Delusions
- Disorientation
- Hallucinations (usually visual)
- Altered sleep/ wake cycle
- Psycho-motor agitation or somnolence
- Decreased cognitive function

Delirium Is Deadly

Delirious patients

- Stop eating
- Stop drinking fluids
- Stop taking important medications
- May fall and injure themselves
- Often are placed in restraints and suffer complications such as aspiration and decubitus
- Interferes with assessment and treatment of other symptoms

Delirium Is Deadly

Delirious patients have a grave prognosis

- The delirium may herald the last days of life in a hospice patient with irreversible illness
- In the last days of life, the treatment may concentrate on the control of the symptoms rather than correction of the underlying cause

Delirium Is Deadly

- Failure to recognize and adequately treat delirium in patients who do not have life-limiting illnesses greatly increases their morbidity and mortality

Delirium Is Common

- 80% of people experience some delirium during the final week of life
- 15–20% admitted to hospitals with cancer experience some delirium

Delirium Causes Extreme Emotional Suffering

- Causes a person to be frightened, agitated, and upset
- Increases the use of restraints

Delirium Causes Extreme Emotional Suffering

Most important, delirium at Life's End interferes with meaningful communication and interaction:

with family and friends

with professional staff (physician, nurses, clergy, counselors)

Management of Delirium

Symptomatic and supportive therapies

Indicated when the burden of evaluation and treatment of the underlying causes of the delirium outweighs the benefits.

Management of Delirium

Considerations

- Work-up of delirium may be limited by the home and hospice setting
- Causes of delirium are often multifactorial
- When a distinct cause is found, it often is irreversible

Management of Delirium

- The comfort of the person suffering from delirium is paramount
- Symptomatic treatment can begin with or without a diagnostic work-up
- Good clinical judgment determines the extent to which to look for and pursue reversible causes of delirium

Management of Delirium

Medications

benzodiazepines opioids
anticholinergics antiemetics steroids

- It is important to simplify the regimen
- It is important to stop unnecessary medications
- It is inappropriate to stop opioids if necessary to control pain and dyspnea
- It may be more reasonable to treat the delirium and continue the medication

Management of Delirium
Differential Diagnosis

- Electrolyte disturbances
- Hypercalcemia
- Hyper/Hypoglycemia
- Hyponatremia
- Uremia
- Hepatic encephalopathy
- Hypoxia

Management of Delirium
Differential Diagnosis

- Infections
  - *Pneumonia*
  - *UTI*
- CNS
  - *Metastatic spread of tumor*
  - *Seizures*
  - *Stroke or bleed*
- Impaction/Constipation
- Urinary Retention

Management of Delirium

Agitation

Treatment with benzodiazepines (Ativan) for agitation associated with delirium may lead to a vicious cycle of escalating doses that only worsens the underlying delirium.

Evaluation of Delirium

- Relevant history
  - *New medications*
  - *Known metastatic disease*
- Physical exam
- Simple blood test
- More extensive work-up (CT scans, X-rays)
  - *May be warranted but physician must make the decision in light of the overall situation and course of the illness.*

Treatment of Delirium
Specific Reversible Causes

- Fluids for dehydration
  IV, PO, SC
- Antibiotics
- Oxygen
- Lactulose
- Bladder catheterization
- Disimpaction

Treatment of Delirium
Fluids for Dehydration

- Caution must be used in using IV fluids
- Placement of IV line and restraints to protect the access may traumatize patient
- Fluid overload with edema and pulmonary congestion can add to suffering at Llife's End
- Use of fluids indicates a cautious, time-limited trial of therapy

Symptomatic Therapy
Neuroleptics

Haloperidol (Haldol) PO, IV, SC
- 0.5–1mg q2–12 hours
- May need to use multiple dose at first to control severe agitation

Chlorpromazine (Thorazine) PO, IV, IM
- 12.5–50mg q4–12 hours
- Use when more sedation is desirable
- Cannot be given SC

Symptomatic Therapy
Neuroleptics

Risperidone (Risperdal)
- 1–3mg PO q12 hours
- Popular because of reports of fewer side effects
- Only comes PO
- Costs $150–$250 for one-month supply

Symptomatic Therapy
Environmental

- Well-lighted room
- Quiet, calm, and familiar surroundings
- Presence of family or staff may be calming
- Restraints, IV lines, oxygen, and other instrumentation may contribute to agitation and suffering

Symptomatic Therapy
Benzodiazepines

Lorazepam (Ativan) PO,IV, SC
- 0.5–2mg q1–4 hours
- Sedation with the addition of a benzodiazepine may be appropriate if symptoms cannot be controlled and the delirium is causing suffering when death is imminent

Delirium
Palliative Care

Palliative-care consultation
may be helpful with delirium
at Life's End

- Reaching correct diagnosis
- Evaluation
- Treatment

Delirium
The Palliative Response

Delirium is common.
Delirium is deadly.
Comfort is paramount.

Selected Readings

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3.2 Anxiety

Key Points

1. Anxiety is an excessive state of apprehension that can contribute to suffering at Life's End by interfering with activities that give life meaning and purpose.

   Anxiety and fear are not the same thing. Fear may be appropriate, adaptive and protective. Anxiety is destructive. It can be continuous and ongoing, of incapacitating intensity, without a clear cause (autonomous), and can result in behavioral changes. Do not dismiss clinical anxiety as "normal" or acceptable.

2. Maintain high index of suspicion for anxiety, especially if behavioral changes manifest. Assess by routinely asking people if they are feeling fearful or anxious.

3. Seek to provide maximum resolution for anxiety.
   - Look for underlying causes;
   - Treat other symptoms aggressively;
   - Stop unnecessary medications and treatment;
   - Educate patient and family about treatment plan;
   - Reassure that some feelings of fear or uncertainty at Life's End may be normal but should be treated if too severe, continuous, or distressing.

4. Differential diagnosis is important in reaching diagnosis of anxiety.
   - Evaluate for pain, delirium, dyspnea, or other physical complication.
   - Consider medication side effect, pre-existing anxiety disorder, withdrawal state, and distress whose source is social, financial, spiritual, or existential.

5. Assess and treat or palliate the source of anxiety.
   - Consider pre-existent and pre-morbid depression and anxiety, Post-Traumatic Stress Disorder (PTSD), and death anxiety.
   - Re-assess control of symptoms, psycho-social-spiritual support, and medication regimen.

6. Medication is often helpful and appropriate in addressing anxiety at Life's End.

   Lorazepam (0.5–2mg q6–8 hours titrated as needed) is the most effective and commonly used medication. Behavioral and relaxation techniques are helpful in a small subset of people.

Anxiety

The Palliative Response

Anxiety versus Fear

Anxiety and fear are not the same.

Fear

- May be appropriate and adaptive
- Can be protective

Anxiety

Anxiety contributes to suffering at Life's End.

- State of apprehension, worry, uneasiness
- May arise from unknown internal source
- May be excessive/overwhelming response to external source
- Can be destructive

Signs of Distressing Anxiety

- Tension, restlessness
- Social withdrawal
- Avoidance
- Substance use and self-medication
- Rumination and dread
- Decreased capacity to cope

Anxiety at Life's End

- Prevalence is not clearly defined
- Often trivialized or dismissed
- Often is expected and accepted as inevitable
- Limits participation in planning for Goals of Care and for "living life"

Secondary Suffering

- Insomnia
- Depression
- GI upset
- Dysphagia
- Fatigue
- Withdrawal from social supports

Indications for Intervention

- Incapacitating intensity

  Anxiety exceeds capacity to bear suffering
- Behavioral changes

  Interferes with activities that give life meaning
- Continuous and ongoing

Assess Frequently

- Maintain high index of suspicion about anxiety
- Routinely ask patients if they are fearful or anxious
- Assess for causes when there are behavioral changes

Assess Cause

Physical

- Control of pain, dyspnea, other physical symptoms

Emotional

- Consider pre-existent depression and anxiety disorders
- Post-Traumatic Stress Disorder (PTSD)
- Assess emotional support

Assess Cause

Social and Spiritual

- Reassess support in community
- Contact pastoral care
- Contact Social Work services
- May need respite care or transfer to another venue of care if support is lacking and cannot be provided

Death Anxiety

- "Everyone wants to go to heaven, but no one wants to die to get there."

  —H. L. Mencken

- "I don't mind dying; I just don't want to be there when it happens."

  —Woody Allen

Differential Diagnosis

- Pain
- Delirium
- Fear
- Dyspnea
- Other physical complication
- Side effects of common medications
- Pre-existing anxiety disorder
- Withdrawl state
- Existential distress
- Social distress
- Financial distress
- Spiritual distress
- Coping style (type A)

Medications That May Contribute to Anxiety

- Theophylines
- Caffeine
- Albuterol
- Akathisia from antiemetics
- Withdrawal from opioids, benzodiazepine, or other substances

Medical Treatment

Medication is often helpful for anxiety at Life's End

- Lorazepam

  The most commonly used and effective

  0.5–2mg q6–8 hours titrated as needed
- Buspar probably not a good choice for immediate relief
- Xanax may have too short a half-life

Anxiety at Life's End

The Palliative Response

- Address patient's concerns to allay fears and reduce anxiety
- Evaluate other causes
- Treat other symptoms aggressively
- Stop unnecessary medications/ treatments
- Educate patient and family

  Anxiety at Life's End is common

  Treatment plan

  Solicit support and care
- Add medical treatment as necessary

Indications for Consultation

- PTSD
- Pre-existing anxiety disorder
- Anxiety not responding to management
- Consultation resources

  Palliative care

  Psychiatry

Anxiety at Life's End

Anxiety contributes to suffering and interferes with important personal work at Life's End.

Selected Readings

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Key Points

1. Depression is common at Life's End.

   While depression is common, it is not universal at Life's End. Sadness is common but, unlike depression, sadness is not overwhelming, continuous, and pervasive. If the sadness a patient experiences is interfering with other important activities, it is probably depression.

2. Depression is often best diagnosed by asking people if they are depressed.

   Somatic symptoms like fatigue, appetite, and change in sleeping patterns cannot be used to diagnosis depression because they are present from other physical causes. Asking people directly to report if they are depressed is the most effective screening tool.

3. Anhedonia often accompanies depression.

   Anhedonia is the inability to experience pleasure. Even people at Life's End should be able to identify things, like family or friends, which still bring pleasure to their lives.

4. Uncontrolled physical and social suffering worsens depression.

   Good control of physical symptoms, especially pain and dyspnea, and social support in the residential setting at Life's End may help relieve depression.

5. Depression may respond to treatments like Selective Serotonin Reuptake Inhibitor (SSRI) and psychotherapy in the last months of life.

   Patients who have a better functional status may respond to SSRI in the last few months of life.

6. Depression may respond to treatment with psycho-stimulants in the last weeks or days of life.

   Methylphendalate (Ritalin) may be effective in treating depression within a few days of starting the medication. This might be helpful in the last few days of life or while waiting for an SSRI to work.

Depression

The Palliative Response

Depression Is Common at Life's End

- Clinical depression is never "appropriate"
- Some surveys report depression in up to 50% of palliative care patients
- Unrecognized and untreated depression causes substantial suffering at Life's End

Depression Can Be Diagnosed at Life's End

- Patients are often able to self-report if they are depressed
- Asking a patient "Are you depressed?" is a good screening test for depression
- Persons who say they are depressed probably are

Somatic Symptoms

Somatic symptoms are poor indicators of clinical depression because they can almost always have other causes.

- Fatigue
- Weakness
- Change in sleep patterns
- Change or decrease appetite and weight loss
- Constipation

Anhedonia

Marker for Depression

Anhedonia (inability to experience pleasure)

- Can be a marker for depression regardless of whether the patient self-reports depression
- A patient who cannot stand the sight of grandchildren, previously the light of his/her life, is depressed

Suicide and Assisted Suicide

Requests for assisted dying

- Depression is a factor in requests for assisted dying

Suicide assessment and prevention

- "Have you thought of suicide?"
- "Do you have a plan?"
- "Will you contract with me that you will not kill yourself?"

Addressing Depression

Increase the capacity
to bear suffering

- Good pain and symptom control
  - *Uncontrolled pain or other symptoms contribute greatly to depression*
- Assist to maintain independence and Activities of Daily Life
- Social support
  - *Home hospice*
  - *Encourage increased contact to maintain ties*

Treating Depression

Antidepressants

Serotonin re-uptake inhibitors

- A mainstay for treatment of depression in palliative care
- Be aware of side effects such as anorexia
- Use in patients whose prognosis offers time for the treatment to be effective (2 to 6 months and functional status)

New atypical antidepressant holds promise

Treating Depression

Psychotherapy

- Formal psychotherapy is not commonly used in the palliative care/hospice setting
- Supportive counseling, listening, and attending to concerns can help support patients and families and increase the capacity to bear suffering
- Psychotherapy may be more directive and focused on problem-solving

Treating Depression

Psychostimulants

- Sometimes helpful in the last few weeks or days of life when depression is a major contributor to suffering
- If effective, will usually help within a few days rather than weeks-to-months
- May be helpful in conjunction with SSRI to treat symptoms quickly while awaiting the effect of the SSRI

Psychostimulants

Methylphendalate (Ritalin)

- Begin with 2.5–5mg at breakfast and lunch
- Titrate to effective dose at 5–15mg am and lunch
- Observe for adverse effects
  - *Anxiety*
  - *Insomnia*
  - *Agitation*

Depression

The Palliative Response

Unrecognized and untreated depression causes substantial suffering at Life's End.

Screen for it.
Recognize it.
Treat it.

Clinical depression is never "appropriate."

Selected Readings

Overview

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Screening for Depression

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3.4 Grief and Bereavement

Key Points

1. Grief is a universal response to any kind of loss.

    The grief response is emotional, cognitive, and behavioral. Examples of losses occasioning grief include loss of job, loss of friendship, loss of child departing for college, and loss of physical ability.

2. The experience of grief and loss is particularly complex and intense at Life's End.

    Everyone involved experiences grief: the dying person, the family and significant others, and caregivers and medical providers—including the physician.

3. Some persons may require intervention for complicated or pathological grief.

    Complicated grief is more intense, prolonged, and disabling and may endanger the bereaved person by becoming self-destructive. Manifestations include self-neglect, substance abuse or other harmful coping behaviors, depression, and suicidality. The Palliative Response to grief uses a multidisciplinary approach including pastoral care, counseling, and medical assessment to monitor the bereavement progress and to intervene in complicated grief.

4. We now know that the stages of loss described by Kubler-Ross are neither predictable nor neatly progressive.

    Manifestation of grief may oscillate back and forth between stages, and elements of different stages may occur simultaneously. "Getting stuck" in one stage of grief is a sign of complicated bereavement.

5. Normal grief includes an initial sense of disintegration—a period of feeling less whole and complete—followed by reintegration that incorporates the loss into one's sense of self.

6. Discussing honestly what is happening and what is likely to happen avoids mixed messages and allows the patient and family time for preparation.

    Patients need time to review their lives. Loved ones need to plan for a future without the patient. Honesty allows everyone to expect, understand, and prepare for losses and to attend to needs in all domains of suffering.

Grief and Bereavement

The Palliative Response

Grief Is Universal

- Grief is a response to loss
  - *Emotional response*
  - *Cognitive response*
  - *Behavioral response*
- Grief is experienced with many kinds of losses
  - *Loss of job*
  - *Loss of friendship following disagreement*
  - *Loss of child departing for college*
  - *Loss of physical ability*

Grief and Loss at Life's End

- Particularly complex and intense
- Experienced by everyone involved
  - *Dying person*
  - *Family*
  - *Significant others*
  - *Caregivers and medical providers, including physicians*

Anticipatory Grief

- Who?
  - *Dying patient*
  - *Loved ones*
- When?
  - *Prior to death*
- Why?
  - *In anticipation of the impending loss*

Bereavement

- What?
  - *Grief*
  - *Mourning*
- Who?
  - *Family, friends, personal caregivers*
  - *Medical professionals*
- When?
  - *After the death of the patient/loved one*

Complicated or Pathological Grief

Indications and manifestations

- More intense and prolonged
- Disabling (depression, self-neglect)
- Endangering (substance abuse, other harmful coping behaviors, suicidal)

Intervention

- Monitor progress of grief process
- Multidisciplinary approach usually indicated *(medical assessment, counseling, pastoral care)*

Dimensions of Grief

Presentation

- Sadness over loss
- Distinguished from depression (which is marked by lack of self-worth)
- Often comes in waves
- Triggers may or may not be predictable

Course

- Often very intense at first
- Intensity/frequency usually diminish over time

Stages of Grief

Interpretation of stages of grief

(described by Kubler-Ross)

- Stages are not predictable
- Manifestation may oscillate between stages
- Progression varies from person to person
- Elements of stages may occur simultaneously

Complicated grief

- Failure to progress through grief
- "Getting stuck" in one stage of grief

Effect of Grief on Sense of Self

Initial sense of disintegration

- Loss of any sort can affect sense of self
- Period of feeling less whole and complete
- Initial sense of disintegration

Process of reintegration

- Fostered by normal grief work
- Fashion a newly integrated self
- Experienced loss finds its place in one's sense of self

The Physician's Role

Honesty at Life's End

Truth-telling in diagnosis and prognosis

- Avoids mixed messages by discussing without ambiguity what is happening and likely to happen
- Allows patients to review their lives
- Assists loved ones to plan for a future that necessarily will be very different
- Allows everyone to expect, understand, prepare for loss
- Helps identify and attend to needs/suffering

Honesty Fosters Communication

Five things everyone needs to say at Life's End:

Forgive me
I forgive you
Thank you
I love you
Good bye

The Physician's Role Open Communication

Fostering communication

- Open the door to discussion
- Then listen!

Conversation starters

- "Things have been changing. How are you and your family coping with the changes?"
- "Are you feeling afraid or overwhelmed?"

The Physician's Role
Assess/Treat

- What?

  Symptoms
- Why?

  Foster comfort for patient

  Free energy, and often more time, for patient and family to work through their grief and prepare for the loss of death
- How?

  Aggressively!

The Physician's Role
Familiarity with Resources

- Pastoral care
- Community support groups
- Communities of faith
- Counseling
- Grief and survivor's groups
- Social Work services
- Community mental-health providers

The Physician's Role
At Time of Death

- Respond empathically

  "I am sorry for your loss"

  Offer to call someone
- Be available

  Answer questions

  Give family and friends time to process

  Welcome contact with the family for future questions and needs
- Check back in

The Physician's Role
After the Death

- Offer emotional support

  Consider sending cards

  Offer to maintain dialogue with the family
- Offer practical support

  Write necessary letters

  Sign necessary forms

  Reassure family you will be helpful
- Offer availability

  Often nagging questions come up later

Bereavement
Follow-up Programs

- Who?

  Medicare hospice programs

  Palliative-care programs
- Why?

  Help facilitate grief work

  Monitor for complicated grief
- How long?

  Up to one year

Grief and Bereavement
The Palliative Response

Honesty at Life's End allows patient, family, friends, and medical caregivers to expect, understand, and prepare for the loss of death.

Selected Readings

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Family Experience

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Medical Provider Experience

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4.1 Religious and Spiritual Issues: Assessing and Addressing

Key Points

1. Spiritual and religious concerns may develop or intensify at Life's End. Many patients welcome an opportunity to talk about spiritual issues in relation to their health and current life experience. Patients and families often avoid these issues for fear of upsetting each other; many physicians feel unskilled, unprepared, and uncomfortable talking to patients about their spiritual and existential concerns.
2. Use a format, such as "FICA," to elicit concerns and identify sources of support. Normalize the topic.
   Faith—Do you consider yourself a spiritual person?
   Importance—Is faith important to you?
   Community—Are you part of a spiritual or faith community?
   Address—How can I address and respect these issues in your care?
3. Share the patient's wondering and questioning and what it is like to be human and to face Life's End. Do not attempt to answer the unanswerable.
4. Elicit further concerns with open-ended questions.
   Do you have any thoughts about why this is happening to you (your family)?
   Help me understand what you mean.
   Many people with serious illnesses like yours ask such questions.
   That sounds kind of scary or troubling to me too.
   How does this make you feel?
5. Discussion guidelines
   - Empathize and share in the uncertainty;
   - Be guided by the patient's own search;
   - Answer personal questions simply; keep the focus on the patient;
   - Allow time and permission for expression of a range of emotions;
   - Clarify sources of hope, meaning, and support; identify Goals of Care that can help maintain hope; honor preferences at Life's End;
   - Foster religious participation and spiritual practice.

   Pitfalls include trying to "fix" patient's problem, imposing or debating personal religious beliefs, providing inappropriate reassurance, and failing to attend to physician's own faith in light of continued losses.

Religious and Spiritual Issues

The Palliative Response

Religion and Spirituality at Life's End

- Spiritual and religious concerns may develop or intensify at Life's End
- Many patients are thinking about these issues in relationship to their health
- Many patients welcome an opportunity to talk about religious and spiritual issues as they relate to their current life experience

Barriers to Addressing Religious and Spiritual Issues

- Many persons have not expressed their existential concerns at Life's End for fear of upsetting families and friends
- Many physicians feel unskilled, unprepared, and uncomfortable talking to patients about religious and spiritual concerns

Getting Started

- Ask open-ended questions
- Use a format
- Listen and respond empathically
- Be familiar with resources
  Pastoral care
  Social Work and counseling
  Communities of faith

The FICA Format*

- **F**aith
- **I**mportance
- **C**ommunity
- **A**ddress

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Faith

"Do you consider yourself a spiritual person?"

"Is faith important to you?"

- Most patients can answer this kind of question
- Include question in social history
- Normalize discussion of faith as part of routine and not a topic indicating that patient is "imminently dying"

Importance

"Is your faith important in your life at this time?"

"Have you been able to take comfort from your faith?"

- May reveal sources of strength and support
- May guide physician in assisting patient to maintain sources of support

Community

"Are you part of a spiritual or faith community?"

- May reveal a source of support
- May reveal that individual has become isolated from faith community

  Frequent occurrence when chronic illness prevents participation in faith community

  Physician may be able to foster re-connection

Address

"How can I address and respect these issues in your care?"

- Patient may have important beliefs, practices, and rituals that are not part of your tradition
- Understanding patient's tradition early on allows the physician to be sensitive to needs

Patient's Response

Many patients:

- Speak openly
- Are grateful to physician for asking about this important part of life
- Express no specific concerns or needs

When Patient Voices Concern

Respond with:

- Open-ended questions
- Comments to normalize the concern

  "Help me understand what you mean."

  "Many people with serious illnesses ask such questions."

  "That sounds scary to me too."

  "Do you have any thoughts about why this is happening to you (your family)?"

  "How does this make you feel?"

Discussion Guideline

Share versus Fix

Do:

- Share patient's wondering and questioning
- Share in what it is like to be human and to face what is at Life's End

Do not:

- Do not try to resolve (fix) the patient's problem
- Do not try to answer unanswerable questions

Discussion Guideline
Follow versus Lead

Do:

- Stay within physician's role and expertise
- Be guided by patient's own search

Do not:

- Proselytize
- Try to convert a vulnerable individual
- Impose personal religious or spiritual beliefs

Discussion Guideline
Support versus Reassure

Do:

- Allow time and permission for people to express emotions
- Develop comfort with tears and range of feelings

Do not:

- Do not offer premature or inappropriate reassurance
- Do not be a phony

Discussion Guideline
Questions about Physician's Beliefs

- Answer simply

  "I would like to keep the focus on you rather than me"

  "I am a person of faith"
- Avoid a religious debate
- Most patients are grateful that physician is interested in this important part of who they are

Steps of Palliative Response
Assess

For patients with life-threatening and life-limiting illness

- Clarify sources of hope and meaning
- Identify Goals of Care

  Maintain hope

  Honor preferences at Life's End

Steps of Palliative Response
Support

- Mobilize resources

  Healthcare team

  Patient's community and community at large
- Patient's spiritual/religious practice

  Solace

  Meaning

  Hope

  Connection

Steps of Palliative Response
Self-Care for the Physician

- Develop healthy personal responses to experiencing the repeated loss of death
- Self-monitor and seek assistance as needed for:

  Depression

  Substance abuse

  Burn-out

Selected Readings

Religion and Spirituality at Life's End

Daaleman, T. P. and L. van de Creek. "Placing Religion and Spirituality in End-of-life Care." *Journal of the American Medical Association* 284 (2000): 2514–2517.

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Listening and Caring/FICA

Puchalski, C. M. "Spirituality and End-of-life Care: A Time for Listening and Caring." *Journal of Palliative Medicine* 5 (2002): 289–294.

Redefining Hope

Parker-Oliver, D. "Redefining Hope for the Terminally Ill." *American Journal of Hospice and Palliative Care* 19 (2002): 115–120.

4.2 Spiritual Distress: Fostering Transcendence at Life's End

Key Points

1. Spiritual questions are common at Life's End and a major source of distress for some persons.

   The spiritual dimension is broader than formal religious beliefs and includes existential questions concerning "why things happen." Most patients think about spiritual issues and are open to discussing them with medical providers.

2. Individuals at Life's End often struggle to maintain connections and to achieve a sense of transcendence over death.

   Transcendence is an achieved state of meaning and hope, providing connections with family and others across life-changing events and ultimately even death itself.

3. Life's End threatens the sources of meaning by which persons have defined themselves.

   Examples of sources of meaning are family, children, religious faith, career, patriotism and country, friends and community, material possessions, pets, hobbies, causes, civic clubs, party affiliations, the arts, and nature.

4. Patients often struggle to maintain meaningful roles even when they can no longer perform them effectively.

   The palliative response to this struggle is to assist the person to reframe and explore sources of meaning and to strengthen, maintain, and develop connections.

5. The palliative response to spiritual distress includes acknowledging, normalizing, and discussing the distress while responding effectively to all forms of suffering.

   Truth-telling helps individuals decide how to plan and prioritize family and other responsibilities. Attempting to shield people from "harsh" reality may lead them to put off work and activities important to them. Refer to pastoral care and/or the faith community as appropriate for each individual.

6. Assist with spiritual distress by reframing the process of "helping" to a focus on supporting.

   Support with truth and honesty. Support to live life fully. Support to live with joy, expectation, and hope. It is not within our power to do this for others; rather, we must support people as they find their way.

Spiritual Distress

The Palliative Response

Spiritual Questioning at Life's End

- Common

  Most patients have been thinking about spiritual issues and are open to discussion with physician
- Can be a major source of distress
- Existential

  Why *things happen*

  Not answered by science and medicine, which address how *things happen*

  Extends beyond formal religious beliefs

Fostering Transcendence

- Transcendence is a state of meaning and hope providing connection with family and others:

  across life-changing events

  ultimately across even death itself
- Individuals at Life's End often struggle:

  to maintain connections

  to achieve a sense of transcendence

Examples of Transcendence

- If a member of your family has died, do you still consider this person a part of your family?
- If so, you have achieved some degree of transcendence over death, since you are maintaining a connection with the person who has died

Life as Defined by Meaning

Examples of things
that give life meaning:

Family
Children
Religious faith
Career
Patriotism and country
Friends and community

Life as Defined by Meaning

The list continues:

Material possessions
Pets
Hobbies
Causes, civic clubs, party affiliations
The arts—music, literature, visual arts
Nature

Life's End Often Threatens Our Sources of Meaning

> "Everyone wants to go to heaven, but no one wants to die to get there."
>
> —*H.L. Mencken*

Changing Relationship to Sources of Meaning

The patient's struggle

- To find meaning when he can no longer maintain roles that gave life meaning
- May attempt to maintain meaningful roles beyond ability to perform them

The palliative response

- Reframe and explore sources of meaning
- Strengthen, maintain, develop connections

Suffering with Loss of Sources of Meaning

> "The state of severe distress associated with events that threaten the intactness of a person."
>
> —*E. Cassell, 1991*

Spiritual/Existential Distress The Palliative Response

Ask and listen

- Accept and normalize
- Acknowledge spiritual distress
- Confirm distress as part of suffering at Life's End

Explore

- Be willing and available to discuss spiritual issues
- Help patient incorporate this aspect of personhood into current life and illness

Rx for Spiritual Distress

Tell the Truth

- Offer honest assessment of probable prognosis and course of illness
- Helps patient/family plan and prioritize
- Attempting to shield people from "harsh" reality may result in their inability to accomplish important work of Life's End

Rx for Spiritual Distress
Help Patient Prioritize

- Which is more important?

  Staying in town to take chemo–therapy for stage IV lung cancer?

  or

  Visiting a daughter in another state who has just delivered a new grandchild?
- *Tuesdays with Morrie* shows how an individual may actively "live" at Life's End

Rx for Spiritual Distress
Respond to All Suffering

- Excellent symptom control

  Frees time and energy to work out issues
- Community resources

  Assistance to maintain efficacy at Life's End (e.g., hospice)
- Pastoral counseling

  Refer to pastoral care and/or faith community as appropriate for each individual

Rx for Spiritual Distress
Reframe "Helping"

Help as support

- Support with truth and honesty
- Support to live life fully
- Support to live with joy, expectation, hope

Rx for Spiritual Distress
Reframe "Helping"

Help as support versus fix:

- Not within our power resolve spiritual issues for others
- Must support people to find their way

Rx for Spiritual Distress
Help Patient Leave Legacies

- Write letters and make videos

  (especially for children too young to remember)
- Tell and write stories
- Make scrapbooks
- Distribute personal belongings, mementos, or heirlooms

Rx for Spiritual Distress
Help Patient Make Memories

- Celebrate birthdays and holidays "out of season"
- Family reunions and get-togethers
- Physician can assist with time off from work for family

Selected Readings

Spirituality and Health

Puchalski, C. M. "Touching the Spirit: The Essence of Healing." *Spiritual Life* 1999 (Fall): 154–159.

Overview of Religion and Spirituality at Life's End

Koenig, H. G. "The Role of Religion and Spirituality at the End of Life." *The Gerontologist* 42 (2002): 20–23.

Transcendence at Life's End

Block, S. D. "Psychological Considerations, Growth, and Transcendence at the End of Life." *Journal of the American Medical Association* 285 (2001): 2898–2905.

Byock, I. "The Meaning and Value of Death." *Journal of Palliative Medicine* 4 (2002): 279–288.

Discussing Religious and Spiritual Issues at Life's End

Lo, B., D. Ruston, L. W. Kates, et. al. "Discussing Religious and Spiritual Issues at the End of Life: A Practical Guide for Physicians." *Journal of the American Medical Association* 287 (2002): 749–754.

The Palliative Response

Comfort Care in the Last Hours of Life

Admit to: Location and Initiate Comfort Care Order Set
Diagnosis: (i.e. Metastatic Lung Cancer/Pain Crisis)
Condition: Grave
Resuscitation Preferences: Do Not Attempt Resuscitation (DNAR)
(if not, document exact status)

Diet
- Order a diet; patient may improve and desire to taste food (select from CPRS order set)
- Full liquid instead of clear liquid (can advance if tolerated) (more palatable, easier to swallow, less likely to cause aspiration)
- May have food brought in by family
- Allow patient to sit up for meals; assist to eat

Activity
- Allow patient to sit in chair if desired and to use bedside commode
- Allow family to stay in room with patient

Vital Signs
- Minimum frequency allowed by policy
- Limit notification orders to those necessary (review options on CPRS)
- Frequent monitors can alarm patient and family
- Numbers can distract staff/family from patient

IV Considerations
- Starting is often difficult and painful, often has no benefit for patient
- Presence of edema indicates that patient is not dehydrated
- Many patients have fluid overload, edema and pulmonary congestion
- **Oral hydration is a reasonable compromise**
- **(or) If IV fluids are used, suggest a limited time trial, such as a 1000–1500 cc D5½ NS over 6 hours** (Select from CCOS on CPRS)

Subcutaneous (SQ) Line
- Small IV or butterfly needle inserted directly under the skin (often on the abdomen or thigh)
- For injecting small volumes of medicines when oral route unavailable
- Avoids burden of finding/maintaining IV access

Orders for Dyspnea
- Oxygen 2–4 liters nasal prong; avoid face mask
- Usually do not recommend monitoring oxygen saturation or telemetry
- **For persistent dyspnea, use opioids,** blow air on face with bedside fan, turn, reposition, sit up. Nebs may be helpful.

Hygiene
- Avoid Foley catheter if possible (may be helpful for hygiene in select patients, e.g., obese or immobilized patients)
- Diapers and cleansing may accomplish same thing
- Delirious patient may pull on bladder catheters
- Check all patients for impaction; suppository may be helpful
- Consider evaluation by skin-care nurse

Comfort Care in the Last Hours of Life: Side One

Notify Pastoral Care and Social Work of admission.

Avoid restraints.

Pain and Dyspnea

- Opioids are usually the most effective in this setting
- Calculate morphine equivalents used in recent past; adjust as needed
- Usually stop sustained-released medicines and use immediate-release
- Morphine concentrate 20mg/ml concentrate
    - a. Start with MS 5mg to much higher dose based on recent use q2 hours. *Offer—patient may refuse*
    - b. Morphine Sulfate 2–4 subq q2 hours (1/3 the oral dose) *Offer—patient may refuse*
    - c. May use IV but shorter half/life and only RN can administer, difficulty with maintaining IV

Pain, Dyspnea, Anorexia, Asthenia, and Depression

- Corticosteroid can have multiple beneficial effects
- Less mineral-corticoid effect than Prednisone
- Does not have to be given in multiple doses
- Dexamethasone 4–8mg PO/SubQ breakfast and lunch

Nausea and Delirium (Phenothazines)

a. Haloperidol 2mg PO or 1 mg SubC q2 hours, x 3 doses total or until settled, then q6–8 hours PRN

b. Patient > 65 years of age: Haloperidol 1mg PO or 0.5 mg SubQ q2 hours, x 3 doses total or until settled

- Nausea usually requires less frequent doses

Anxiety and Seizures (Benzodiazepines)

a. Lorazepam 1mg PO/ SubC q6–8 hours prn

b. Patient > 65 years of age: Lorazepam 0.5 mg–1 mg PO/ SubQ q6–8 hours prn

- May be helpful with anxiety
- Exercise care as delirium can sometimes be mistaken for anxiety
- Effective against seizures only as IV or SQ and not PO

Death Rattle

- Keep back of throat dry by turning head to side
- Stop IV fluids or tube feeding
- Scopolamine patch topical behind ear q3 days
- Atropine eye drops 2–3 in mouth q4 hours or until patch effective
- Avoid deep suctioning. Family can cleanse with sponge sticks

Tips for Comfort and Safety

- Reposition, massage, quietly sit with and speak to patient
- Avoid sensory overload (e.g., TV); soft music instead
- Use bed minder in lieu of restraints to alarm if patient gets up

Assisting Family

- Advise about alerting other family members as to gravity of patient's status
- Facilitate family presence; order permission for family to visit or stay
- Arrange visits of military relatives by contacting Red Cross
- Arrange visits of incarcerated relatives by contacting Warden
- Give family the pamphlet *Gone from My Sight*

Comfort Care in the Last Hours of Life: Side Two

Guidelines for Pronouncement

Preparation before Death Pronouncement

- Be prepared to answer pertinent questions
- Nursing staff can provide wealth of information
- Know recent events, family response and dynamics, and special problems or concerns
- Assess immediate situation
  Death expected or sudden?
  Family present or notified?
  Attending notified?
- Autopsy
  Determine family request
  Consider value of autopsy
- Organ donation
  If family requests, contact organ donation counselor to discuss details
- Faith tradition
  Consider pastoral care contacts
  Honor requirements/procedures/rituals

Entering the Room

- Quiet, respectful attitude
- Ask nurse to accompany for introductions
- Introduce yourself and role: “I am the doctor on call”
- Determine relationships of persons present
- Inform family of purpose; invite to them to remain
- Empathize simply:
  “I am sorry for your loss. This is a difficult time.”

Pronouncement Procedure Clinical Examination

- Check ID bracelet and pulse
- Check pupils for position and response to light
- Check response to tactile stimuli
  Examine respectfully: No sternal rubs or nipple pinches
- Check for spontaneous respiration
- Check for heart sound and pulses
- Record time of death

Guidelines for Pronouncement: Side One

Follow-Up When You Are Patient's Physician

Invite family to contact you over the next few days or months if questions arise or problems occur

Follow-Up When You Are Physician on Call

Assure family you will report death to the attending physician, whom they may contact with questions or concerns

Death Note in Chart

- Date and time
- Name of provider pronouncing death
- Brief statement of cause of death
- Note absence of pulse, respiration, pupil response
- Note if family present or informed
- Note family response if indicated
- Note notification of attending, pastoral care, social work or others as appropriate

Death Certificate

- Locate sample death certificate on unit
- Complete marked sections. Write neatly in black ink.
- Begin again if make an error (cross-outs not allowed)
- Cause of death—primary and secondary

<u>Example:</u> Primary: Pneumonia
Secondary: Advanced Alzheimer's Dementia

- "Contributing but not primary" section. List other illnesses possibly linked to patient's disability or service connection (e.g., Agent Orange, Asbestosis)
  Documentation assists family to obtain benefits
  Families appreciate and respond to a respectful and kind approach to this final medical act

If families should contact you later

Take time
Inquire about family members
Listen carefully
Respond empathically

Death pronouncement is the final medical act.
Handle with care.

Guidelines for Pronouncement: Side Two

The Palliative Response

Opioid Equianalgesic Conversion Table

(Dosing in mg unless listed)

ORAL	OPIOID AGENT	IV/IM/SQ
30	Morphine (MSC, OSR, Roxanol^{TM})	10
8	Hydromorphone (Dilaudid^{TM})	2
20	Methadone (Dolophine^{TM})	–
300	Meperidine (Demerol^{TM})	100
30	Oxycodone (Roxicodone^{TM}, OxyContin^{TM})	–
4 tabs	Oxycodone 5mg/APAP 325mg (Percocet^{TM})	–
6 tabs	Hydrocodone 5mg/APAP 500mg (Lortab5^{TM})	–
6 tabs	Codeine 30mg/APAP (Tylenol #3^{TM})	–
200+	Codeine	–

FENTANYL PATCH CONVERSION

25mcg/hour topically exchanged every 72 hours equivalent to:
Morphine 15mg IV or 45mg PO per day
Hydromorphone 3mg IV or 12mg PO per day
Percocet^{TM}/ Lortab5^{TM} /Tylenol #3^{TM} 9 tabs per day

USUAL INITIAL PCA DOSES

Morphine 1–2mg (10 mg/ml)
Hydromorphine 0.25–0.5mg (0.5 mg/ml)

- INTERVAL LOCK-OUT: Every 10–15 minutes
- FOUR HOUR LIMIT: None

1. After 24–48 hours of consistent PCA use for chronic pain, a Continuous Hourly Infusion Rate may be set at 50–75% of the daily PCA use. If a Continuous Hourly Infusion Rate is initiated, the PCA DOSE should be adjusted to 50 to 200% of this Continuous Hourly Infusion Rate every 10–15 minutes based on the patient's response.
2. Decrease the Continuous Hourly Infusion Rate as PCA use declines to avoid overmedication.
3. Never use Continuous Rate in acute pain of limited nature.

Opioid Equianalgesic Conversion Table: Side One

- Dosing tables only provide conversion estimates. Patient response may differ. Consider partial cross-tolerance when changing between narcotic agents. A well-controlled patient may require a 25% or greater dose reduction of the newly chosen agent. Opiate agonists have different durations of action, extent of oral absorption, and elimination, which may affect patient response.

- Methadone has a longer elimination half-life than duration of action and may require dose adjustment to prevent over accumulation.

- Meperidine is not indicated for prolonged therapy (greater than five days), and Normeperidine (a metabolite) may lead to seizures in patient with decreased renal function. Oral absorption of Meperidine is less reliable than other opiates and is not recommended. Its absorption, elimination, and toxicity can be affected by many drug interactions that inhibit or enhance its metabolism.

- The daily dose of acetaminophen (Tylenol) should not exceed 4 grams in a 24-hour period. This means that patients cannot use more that 8 Lortab or Tylox tablets, or 12 Percocet tablets in a 24-hour period without exceeding this limit. If pain cannot be controlled with this number of tablets, opioids not in combination with acetaminophen should be used.

- Darvon and Darvocet are ineffective analgesics and their use is discouraged.

- Constipation is secondary to opioids is common. A large bowel stimulant such as Senna or Dulcolax should be prescribed along with opioids.

- Oxycontin should not be prescribed at a less than 12-hour interval. MsContin and Oromorp should not be ordered at a less than 8-hour interval

Opioid Equianalgesic Conversion Table: Side Two

Sharing Bad News

First Step in Planning Care
- Helps develop therapeutic relationship
- Discuss agenda of patient/family first
- Let physician priorities flow naturally from the patient/family (e.g., discussion of resuscitation and other advance directives)

Discussion Agenda
- Physical care—Setting and level of residential care
- Social care—Family and financial issues (e.g. dependence/disability)
- Emotional care—Sources of support
- Spiritual care—Sources of meaning

Physician Role
- DO NOT DELEGATE sharing bad news
- Sharing bad news is physician's role
- Patients often accept bad news only from MD
- MD best prepared to interpret news and to offer advice

Physician Preparation
- Confirm medical facts; plan presentation
- Make only one or two main points; use simple, lay language

Setting the Stage
- Choose appropriate, private environment (Neither hallway nor curtain provide privacy)
- Have tissue available
- Allot enough time (20–30 minutes minimum with documentation)
- Determine who should be present
- Turn beeper to vibrate (avoids interruptions, demonstrates full attention)
- Shake hands with the patient first
- Introduce yourself to everyone in the room
- Always sit at eye level with patient at a distance of 50–75 cm
- Ask permission before sitting on edge of bed
- Arrange seating for everyone present if possible (Helps put patient at ease, prevents patient from hurrying)

Starting the Conversation

ASK: How do patient and family understand what is happening? What have others told them?
WAIT 15–30 seconds to give opportunity for response
LISTEN: Response may vary from "I think I am dying" to "I don't understand what is happening."

- How much does patient want to know?
- Ask patient if he/she wants to know prognosis
- Patient may decline conversation and designate a spokesperson

When Family Wants to "Protect" Patient

- Honor patient's autonomy
- Meet legal obligation for consent
- Promote family alliance and support for the patient
- Ask what family is afraid will happen
- Offer to have family present when you speak to the patient (so they can hear patient's wishes about knowing status/prognosis)

Sharing Bad News

- Give a warning to allow people to prepare
- Briefly state only one or two key points
- Use simple language

STOP:

- Ask questions to assess understanding
- Recommended statement for terminal illness: "This is an illness that man cannot cure."
- Humble statement
- Leaves open the possibility of the miraculous
- Helps change the focus from "cure" to palliation and support

<u>Do not minimize severity of news</u>

Response to Emotions of Patient, Family, and Staff

- Be prepared for a range of emotions
- Allow time for response
- Communicate nonverbally as well as verbally (Usually acceptable to touch patient's arm)

Suggest a Brief Plan

- Medical plan (e.g., control dyspnea, home assistance to help deal with weakness)
- Ancillary support (e.g., social work visits, pastoral care visits)
- Introduce advance care planning ("Sometimes when people die, doctors try to bring them back to life... Have you considered whether you would want this or not?")
- Discuss timeline

Offer Follow-up Meeting

- When? Usually within 24 hours
- Who? For current and additional family members
- Why? To repeat portions of the news
- How? Offer to contact absent family members
  Get permission to share news if necessary
- Next meeting, upcoming decisions, suggest flexible timeline

Ending the Meeting

- ASK: "Do you have any questions?"
- WAIT
- ANSWER
- STAND—An effective way to end the conversation

Sharing Bad News: Side Two

When to Consider Palliative Care

Upon Admission:

Palliative care can often assist in improving symptom control for people with pain or other physical symptoms.

The palliative care team approach can assist you in relieving the emotional, social, and spiritual suffering patients may experience.

Palliative care can help you determine the eligibility of patients for supportive care services such as palliative care clinic, home health, and home hospice, which may provide needed assistance with home services, medications, and nurse case management.

Palliative care can help facilitate patient and family conferences to define Goals of Care, including advanced directives.

Cancer—Any patient whose cancer is metastatic or inoperable.

The Palliative Response

When to Consider Palliative Care

Heart disease
CHF symptoms at rest
EF of < 20%
New dysrhythmia
Cardiac arrest, syncope, or CVA
Frequent ER visits for symptoms

Pulmonary disease
Dyspnea at rest
Signs or symptoms of right heart failure
O2 sat on O2 of < 88%
P CO2 > 50
Unintentional weight loss

Dementia
Inability to walk
Incontinence
Fewer than six intelligible words
Albumin < 2.5 or decrease PO intake
Frequent ER visits

Liver disease
PT > 5 seconds
Albumin < 2.5
Refractory ascites
SBP
Jaundice
Malnutrition and muscle wasting

Renal disease
Not a candidate for dialysis
Creatinine clearance of < 15 ml/minute
Serum creatinine > 6.0

Failure to thrive
Frequent ER visits
Albumin < 2.5
Unintentional weight loss
Decubitus ulcers
Homebound/bed-confined

When to Consider Palliative Care: Side Two