Supporting End of Life Choices

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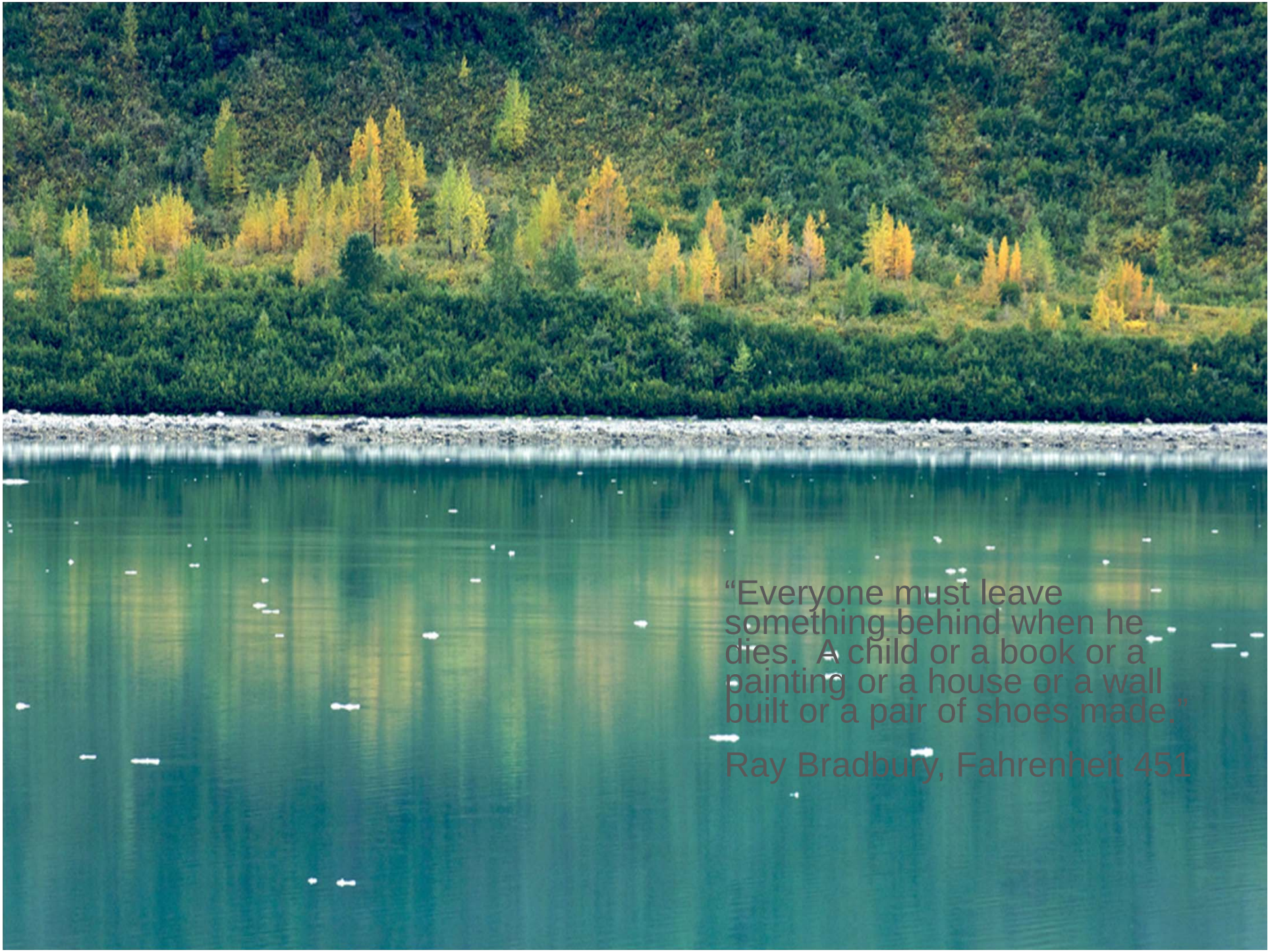

“Everyone must leave something behind when he dies. A child or a book or a painting or a house or a wall built or a pair of shoes made.”
Ray Bradbury, Fahrenheit 451

Average Life Expectancy 2014

Overall	78.8 years
Female	81.2 years
Male	76.4 years
I/DD	73.0 years

The New Old Age: Caring and Coping, Do Not Resuscitate: What Young Doctors Would Choose

Survey of 1,100 physicians

Over 88% would choose no CPR if terminally ill

Palliative Care and End-of-Life Planning

- Advance Directives
  - Durable Power of Attorney for Healthcare
  - Living will
  - POLST

Aging individuals with intellectual disabilities may be denied the opportunity to express their preferences and choices about end-of-life care.

Barriers to end-of-life choices

- Dependent condition
- Lack of education
- Regulatory issues
- Legal arena
- Lack of understanding of capacity
- Fear of liability

Aging with Intellectual Disability

- Reduced functional vision, hearing and balance
- Age-related changes occur earlier
- Higher prevalence of obesity and osteoporosis
- Increased complications of medications
- Higher rates of depression

Aging with Down's Syndrome

- Decreased average life expectancy of ten years
- Earlier loss of adaptive life skills
- High risk of developing Alzheimer's disease

Demographic changes

- 75% of intellectually disabled people live with their families
- 25% of family caregivers are over age 60
- some are now caregivers for aging parents

Key Principles for end-of-life care

- Recognition of differences living with a chronic disability and terminal illness
- Healthcare decision-making is a lifelong process
- Planning for end-of-life care must begin in advance of a terminal illness

- Individuals and families need education and support to make medical decisions
- Don’t exclude people with intellectual disability from participating in rituals of death and grief
- Access to full range of end-of-life care options
- Right to die in their home
- Appropriate pain management

End-of-Life Demographics

- Majority of deaths in older adults
- Seriously ill patients spend most of their time at home, but most deaths occur in the hospital or a nursing home
- Location of deaths vary regionally

Quality of End of Life in the US

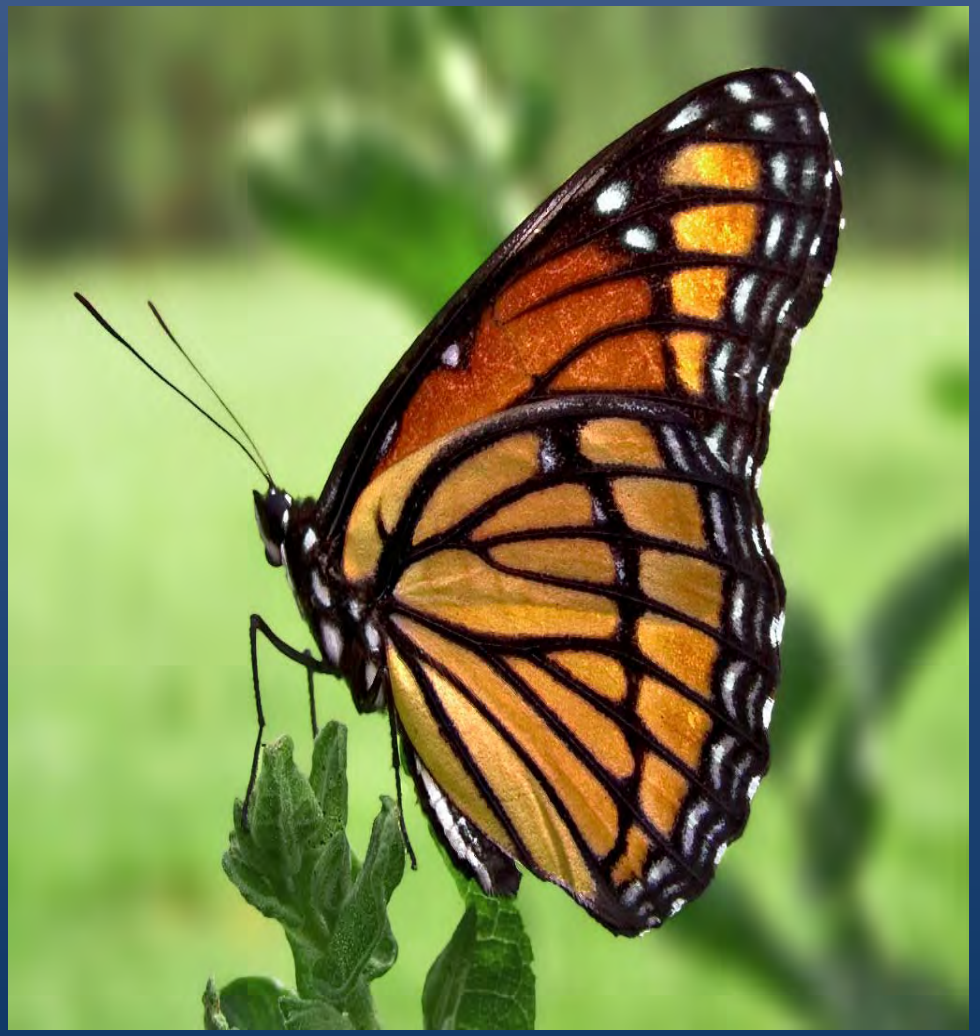
Typical deaths are :

- Slow
- Associated with chronic disease and multiple comorbidities
- ⬆ dependency and care needs

What is Palliative Care????

Interdisciplinary care which aims to relieve suffering, improve quality of life, optimize function, and assist with decision making for patients with advanced illness and their families

Care is offered simultaneously with all other appropriate medical treatments



WHAT IS “HOSPICE”???

- The comprehensive care system for patients who are expected to live ≤ 6 months
- Patient or their proxies must enroll in Hospice
- Patient can be at home or institutional setting

THE HOSPICE MEDICARE BENEFIT

- Certification of expected prognosis by a licensed physician
- Forego curative treatments and agree that the care plan for the terminal illness will be managed by hospice
- Includes: physician services, nursing care, some medications, medical equipment and supplies, short-term respite or inpatient for symptom control, home-health aide, bereavement services

OBSTACLES TO EFFECTIVE HOSPICE CARE

- Limited access to service
- Lack of family or caregiver support
- Late referral
- Difficulty in determining prognosis

STEPS IN COMMUNICATING BAD NEWS

- Prepare
- Establish the patient's level of understanding
- Learn how much the patient wants to know
- Deliver the information
- Respond to the patient's feelings
- Organize a plan and follow-up

PREPARING TO DELIVER BAD NEWS

- Plan your discussion
- Ensure availability of medical facts
- Choose a comfortable and appropriate setting
- Deliver the news personally and privately
- Allow adequate time for discussion
- Minimize interruptions

ESTABLISH THE PATIENT'S UNDERSTANDING

Ask questions such as :

What do you understand about your illness?

When you first had symptom X, what did you think it might be?

What have other doctors told you about your medical condition or tests that you have had?

HOW MUCH DOES THE PATIENT WANT TO KNOW?

- Patients have the right to be told the truth.
- Patients have the right to decline to learn unwanted information.
- A patient may not want to know full details.
- A patient may choose to have a family member or surrogate decision maker informed instead.

DELIVERING BAD NEWS

- Use phrasing to prepare the patient and family
- Sensitive and straightforward manner
- Avoid technical language or euphemism
- Check for understanding
- Clarify difficult concepts

AFTER DELIVERING BAD NEWS

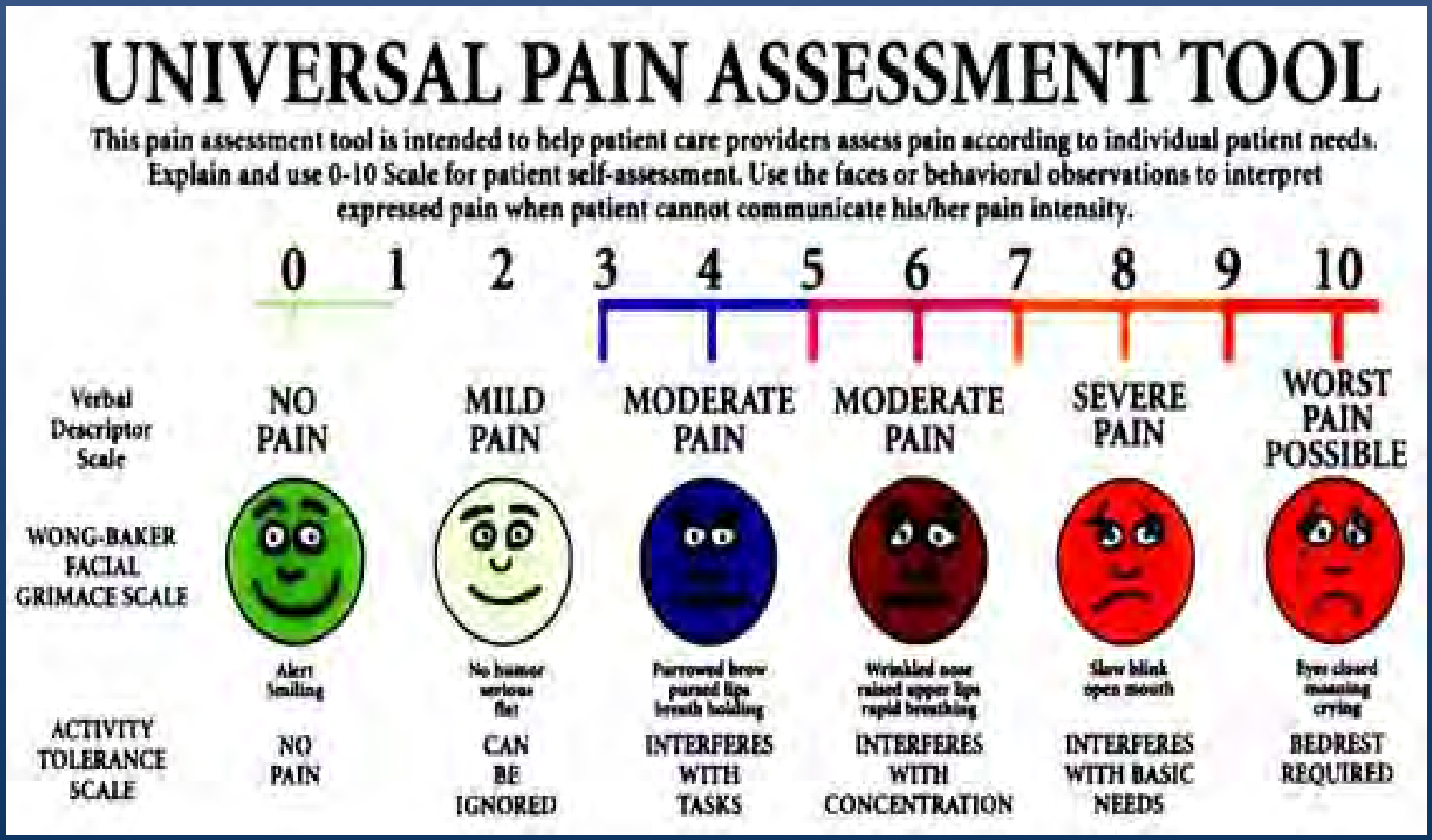
Respond to feelings

- use active listening
- encourage emotional expression
- acknowledge the patient's emotions

Organize a plan and follow-up

- immediately address patient concerns
- set time for follow-up visits, tests, referrals
- provide contact information

EFFECTIVE PAIN MANAGEMENT



EFFECTIVE PAIN MANAGEMENT

- Know the types of pain
- Assess the patient's level of pain
- Minimize pain using nonpharmacologic techniques
- Add pharmacologic analgesia when needed
- Anticipate and manage the side effects of opioids

RELIEF OF NON-PAIN SYMPTOMS

- Constipation
- Nausea & vomiting
- Diarrhea
- Bowel obstruction
- Poor appetite
- Weight loss
- Delirium
- Depression
- Shortness of breath
- Cough
- Loud respirations

ANOREXIA AND CACHEXIA

Loss of appetite is almost universal among terminally ill patients.

- Anorexia in actively dying patients who do not wish to eat should not be treated.
- Treat symptoms of dry mouth.
- Eliminate dietary restrictions. Encourage patients to eat what is most appealing.

DEPRESSION

Under-recognized and undertreated in the terminally ill

- Vegetative symptoms less reliable because of underlying illness
- Look for mood change, suicidal ideation, loss off interest
- Treat: anti-depressants, psychiatric consult, cognitive-behavioral therapy

SUMMARY (1 of 2)

- Palliative care aims to relieve suffering, improve quality of life, optimize function, and assist with decision making for patients with advanced illness and their families.
- Palliative care is offered simultaneously with all other appropriate medical treatment.
- Communicating bad news requires preparation, sensitivity to patient's understanding and needs and an organized plan with follow-up.

SUMMARY (2 of 2)

- Pain should be assessed in all patients and adequately treated with nonpharmacologic interventions and drugs.
- Clinicians should watch for and treat other symptoms which add to the burden of illness.

CASE 1 (1 of 3)

- A 59-year old man with Down's syndrome and Alzheimer's disease is hospitalized for aspiration pneumonia for the second time in 4 weeks.
- He became fully dependent in his activities of daily living over the past year, and he has been losing weight.
- He has been in a nursing home for the past 5 months because he could no longer be cared for by his elderly mother.
- A pressure ulcer developed during his last hospitalization. It is larger with drainage.

CASE 1 (2 of 3)

- The patient became agitated during a dressing change. He was given intravenous morphine and slept for several hours.
- His 83 year-old mother stated that she does not want her son to suffer and asks what can be done to make him more comfortable.
- There is no advance directive.

CASE 1 (3 of 3)

Which of the following is most appropriate?

A. Discharge home on hospice.
B. Discharge to the nursing home on Hospice.
C. Discharge to the nursing home with IV antibiotics.
D. Start continuous morphine for pain control.
E. Surgically treat the ulcer.

CASE 2 (1 of 2)

A 53 year-old woman with mild MR lives with her 79 year-old mother who has worsening dementia. Her brother lives in Connecticut.

No formalized future care plans have been made for this woman. Her mother believes that there will be enough money in her estate to cover in-home care for the rest of her daughter's life.

Her mother is having difficulty caring for her daughter.

CASE 2 (2 of 2)

What interventions can help the daughter now and in the future?

What interventions can help the mother now and in the future?

CASE 3 (1 of 2)

Jenny is a 45-year old woman with Down's syndrome and stage 4 ovarian cancer. She is hospitalized for severe abdominal pain and vomiting.

Her CT of the abdomen demonstrates near-complete obstruction of the colon due to worsening disease.

She is started on IV fluids, IV medications and a nasogastric tube is placed.

CASE 3 (2 of 2)

Her oncologist tells her parents that her condition will not improve with surgery or medications, although a diverting colostomy could be attempted.

What are appropriate next steps?