Overview of Palliative Care

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Percentage of people who receive PC=14%

For children, 98% of those needing palliative care live in low- and middle-income countries with almost half of them living in Africa (WHO website[2], 2022).

Global need for PC = 40 million people

	Early 1900s	Current
Medicine's Focus	Comfort	Cure
Cause of Death	Communicable Diseases	Chronic Illnesses
Death rate	1720 per 100,000 (1900)	821 per 100,000 (2015) 3/1000 in Oman
Average Life Expectancy	50	78.8 US 74.83 IRAN
Site of Death	Home	Hospitals
Caregiver	Family	Strangers/ Health Care Providers
Disease/Dying Trajectory	Relatively Short	Prolonged

Some of the differences in death and dying in society

Question (Preferred Place of Death)

If you had the choice to choose the place you want to die in, where would it be?

Where do people die?

Hospitals	59%
Residences	20%
Nursing Home	17%
Other	6%

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Preferred place of death and end-of-life care for adult cancer patients in Iran: A cross-sectional study

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Palliative Care

The active total care of persons with advanced, progressive diseases

Focus: control of symptoms:

- Physical
- Psychological
- Social
- spiritual

Goal: improve QoL for patients and their families

It may be provided throughout course of disease in conjunction with disease-modifying treatment

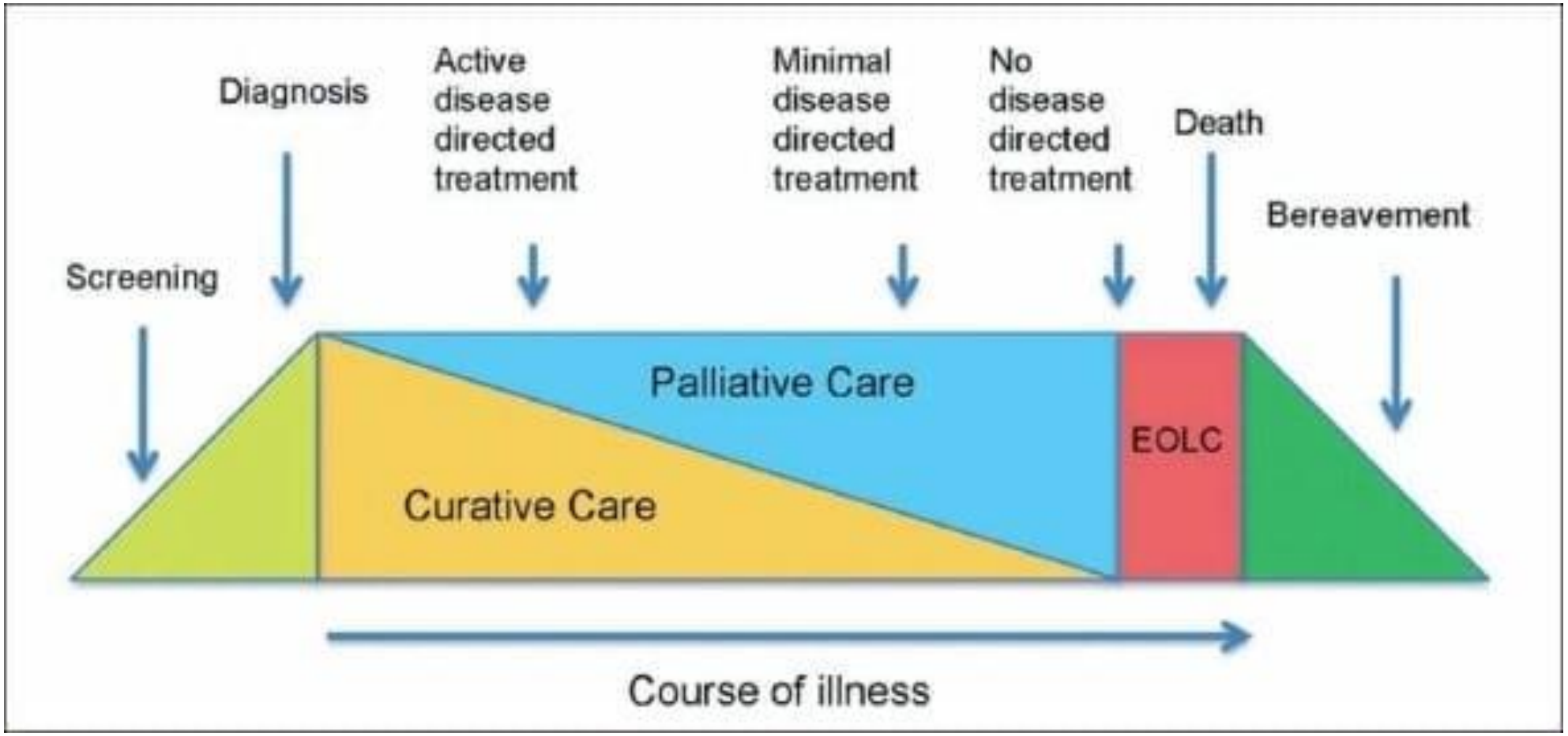
Palliative Care Is:

- ✓ Excellent, evidence-based medical treatment
- ✓ Vigorous care of pain and symptoms throughout illness
- ✓ Care that patients want *at the same time* as efforts to cure or prolong life, when appropriate

Palliative Care Is NOT:

- ☒ Not "giving up" on a patient
- ☒ Not in place of curative or life-prolonging care
- ☒ Not the same as hospice
- ☒ Does not require a DNR order

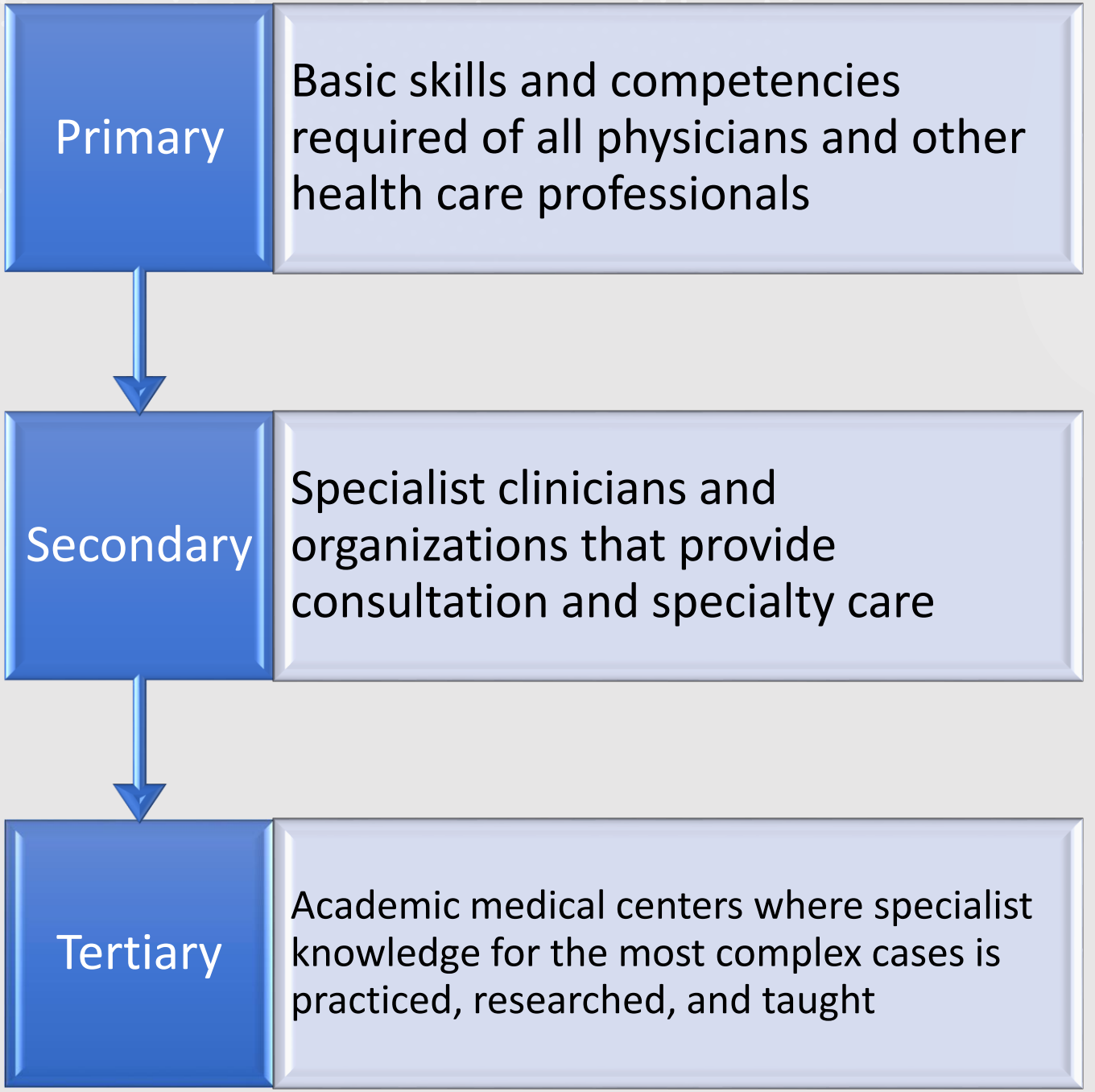
Palliative Care Model



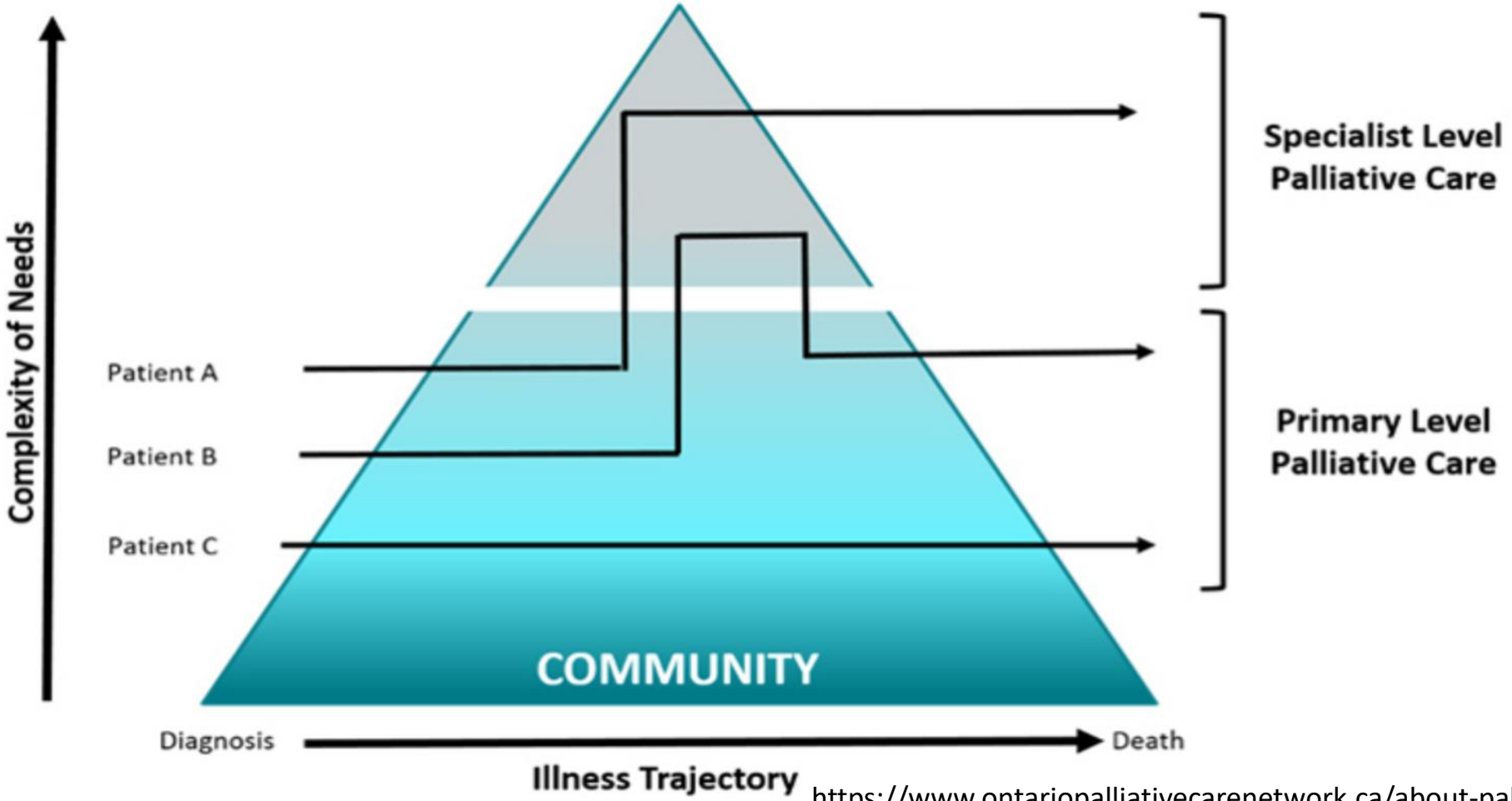
The number of diagnostic groups needing palliative care increases from 18 to 20

- Alzheimer and other dementias
- Arteriosclerosis
- Cerebrovascular disease
- Chronic ischemic heart disease
- Congenital malformation
- Degenerative CNS disease (MS)
- Hemorrhagic fevers
- HIV/AIDS
- Inflammatory CNS disease
- Injury (including poisoning and external causes)
- Leukemia
- Liver disease
- Low birth weight-premature birth-birth trauma
- Lung disease
- Malignant neoplasm
- Malnutrition
- Musculoskeletal disorder
- Non-ischemic heart disease
- Renal failure
- Tuberculosis

Levels of Palliative Care

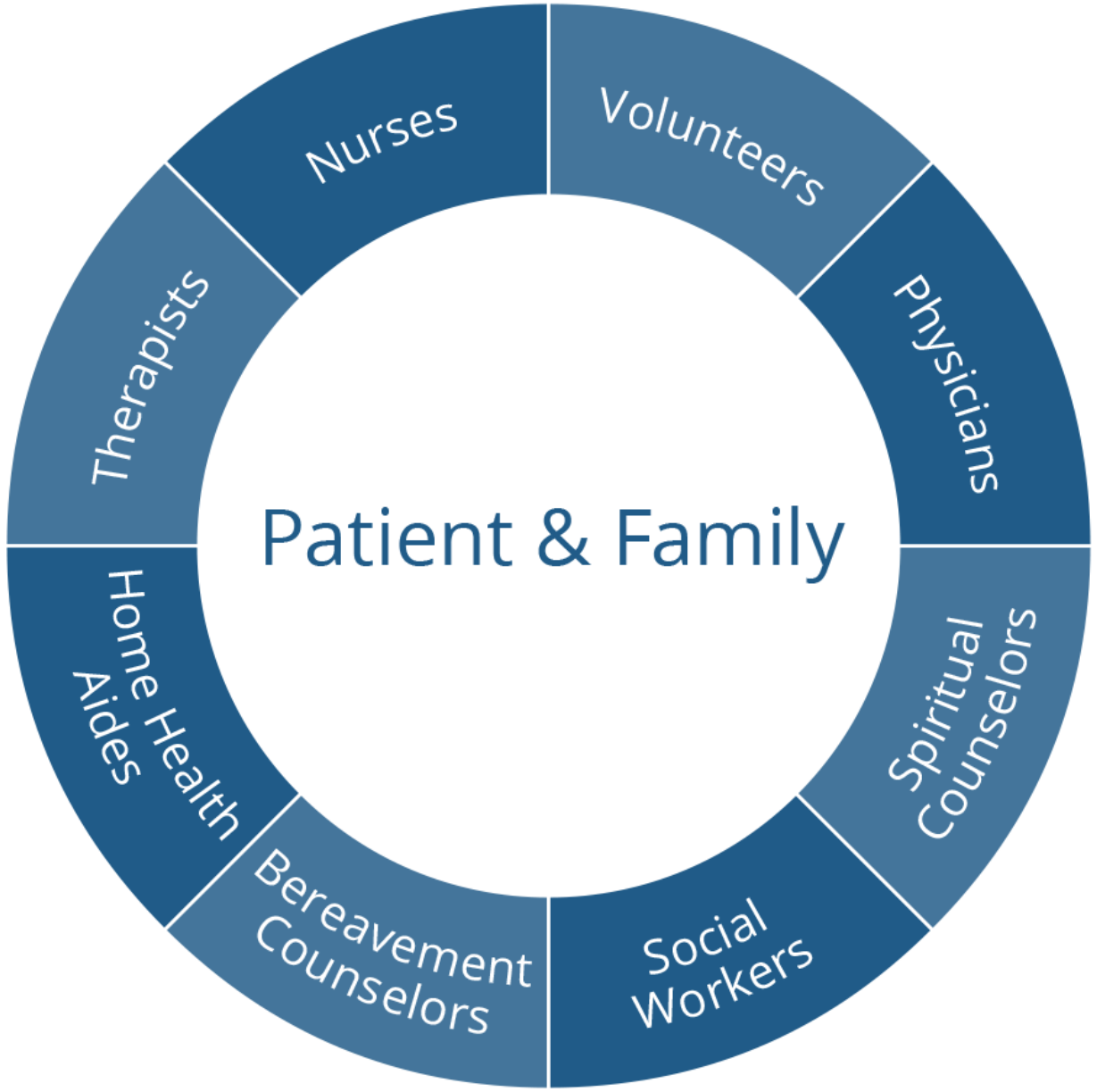


Palliative care is offered by two levels of care providers: primary and specialist. These levels are based on the knowledge and skills of the provider.



https://www.ontariopalliativecarenetwork.ca/about-palliative-care/who-delivers

Stakeholders



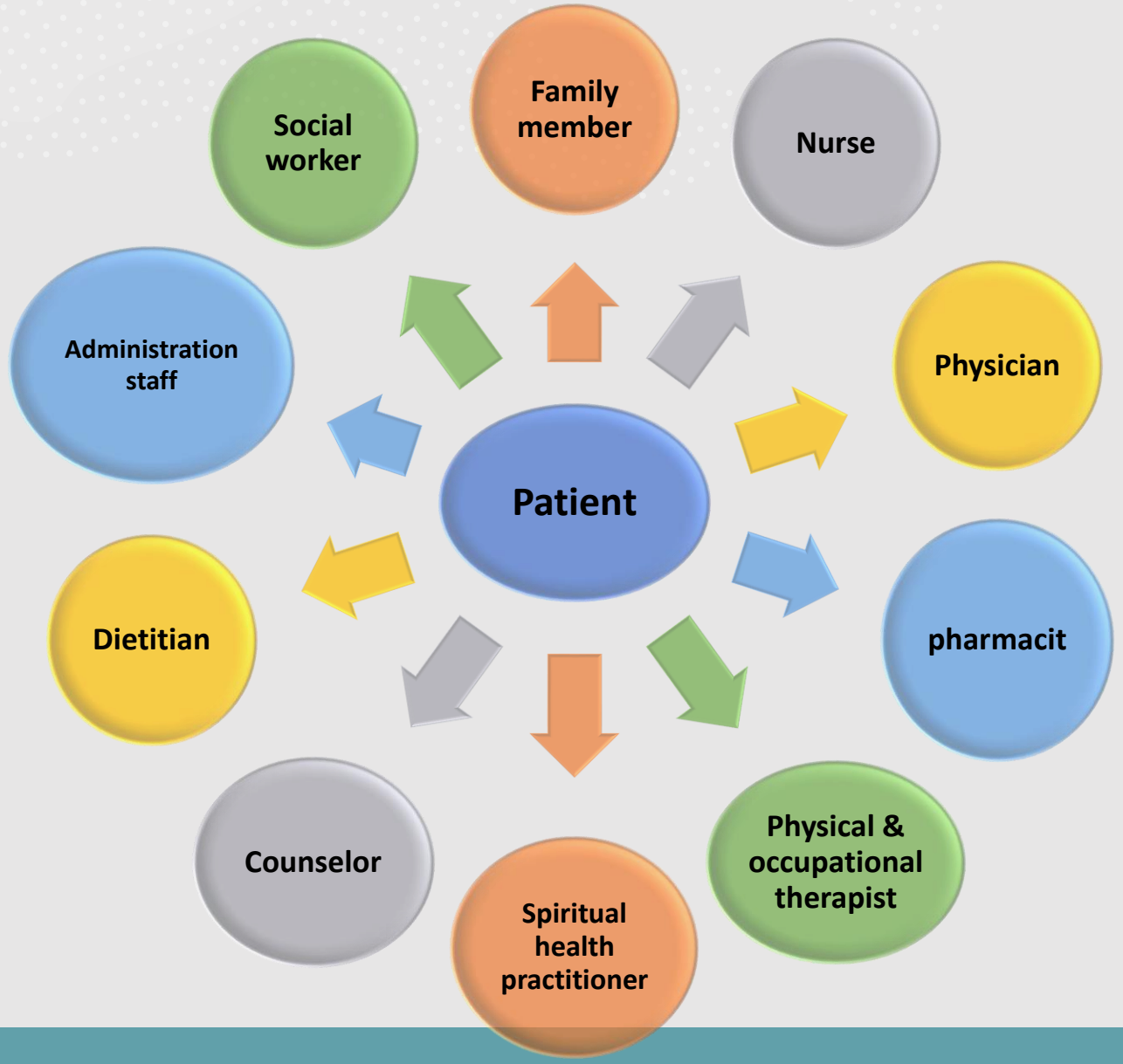
Palliative Care Settings

- Hospital
- Outpatient Clinic
- Home
- Long-term Care & Hospice
- Tele-medicine

Hospital based palliative care

- Hospital based palliative care service includes:
- Palliative care consult teams
- Palliative care units
- Ambulatory palliative care

Hospital / Inpatient Setting



Hospital/Inpatient Setting

- Addressed as applicable in consult:
  - EOL care
  - Goals of care
  - Obtain decision about DNR
  - Symptom management
  - Psychosocial care
  - Pain management
  - Spiritual care

Palliative Care Units

- Transfer to an inpatient palliative care unit is most appropriate for the following indications:
  - Patients who have difficult-to-control symptoms.
  - Medical needs that cannot be optimally managed in another setting.
  - Distressed families in need of a higher level of support.
  - Patients who are imminently dying.

Palliative Care in the Ambulatory Setting

Provide important continuity of care for patients who are discharged from the hospital.

Provide pain and symptom management, psychosocial support, and coordination of home care needs

Palliative Care in the Home or Community

- Home Health Nursing
- Hospice

Physical Aspects of Palliative Care

Symptoms Experienced by Patients

Fatigue	Anorexia	Pain	Nausea
Dyspnea	Constipation	Sedation and Confusion	Xerostomia

Psychological Aspects of Palliative Care

Psychological Care

35-70% of people with cancer suffer from anxiety and depression.

Aspects of psychological health:

- Concerns
- Fears & Anger
- Distress & Anxiety
- Sadness & Depression
- Grief

Communication is vital in this situation.

Spiritual Aspects of Palliative Care

"Spirituality" is difficult to understand

- Stories about life
- Relationships with self and others
- Relationships with music and nature
- Relationship with God or a higher power
- Hope, meaning, and purpose in life
- Religion

Why Spirituality in Palliative Care?

Patients, confronted with mortality, limitations, and loss, wrestle with questions about their life's purpose and meaning amidst suffering.

The search for meaning is one of the primary motivators that keeps us going.

Spiritual well being and meaning are important buffers against hopelessness, depression and desire for hastened death.

Social Aspects of Palliative Care

Incurable illnesses change the social status of the patient.

Besides pain, and other devastating symptoms, patients may suffer from

- The undesirable effects of the disease which affects the patient's appearance
- The loss of social, professional, and familial roles
- The ability to remain independent and function normally
- The perception of the future.

Social support is important not only for the patient, but also for the caregiver.






“Caregiver is a friend or relative who provides unpaid assistance to a person with a chronic or disabling condition.”

Pain Management

Pain: A common problem and the most feared, distressing symptom for some patients in palliative care.

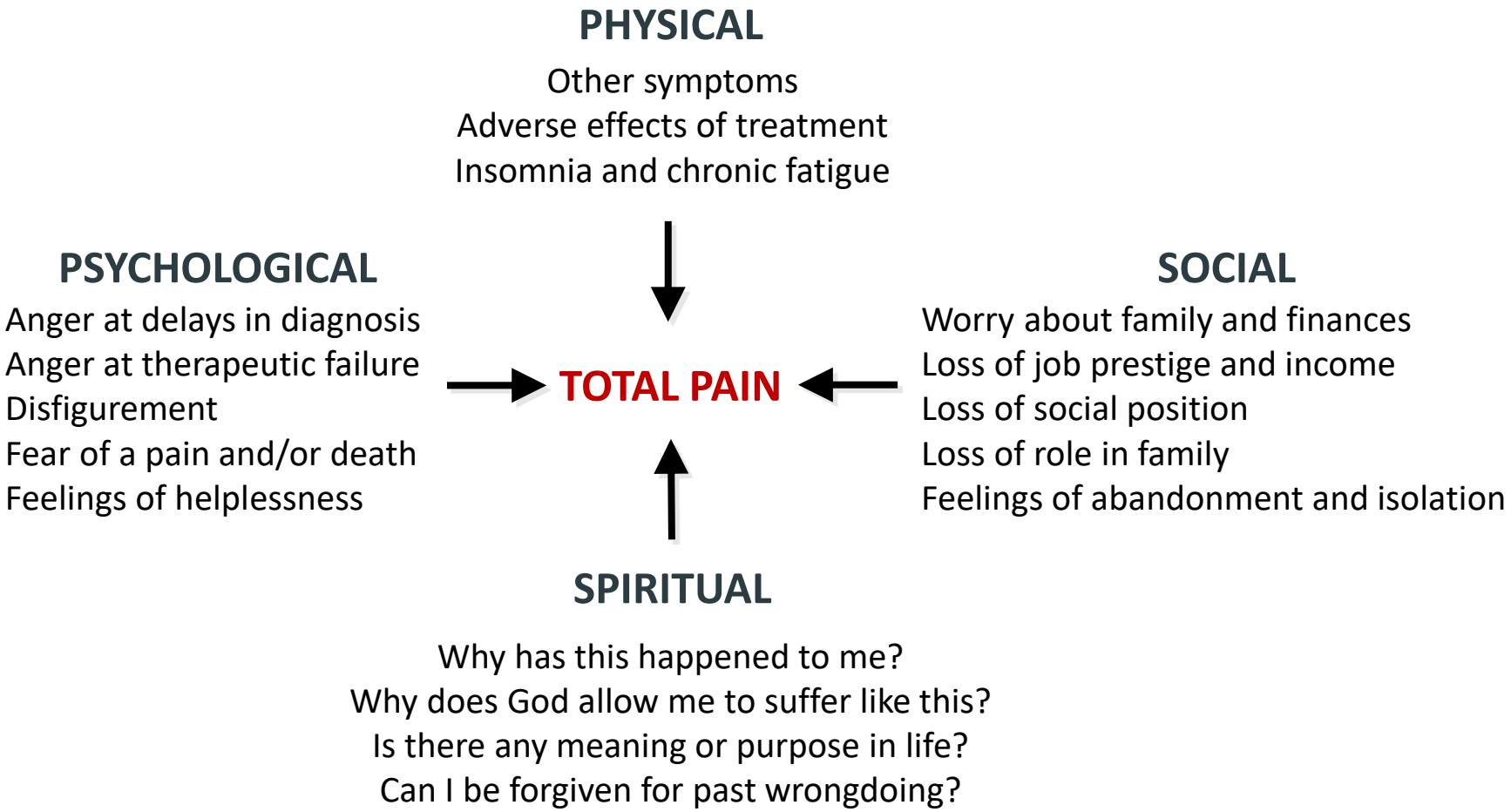
An unpleasant sensory & emotional experience associated with actual or potential tissue damage or described in terms of such damage.

American Pain Society, 1992

Whatever the experiencing person says it is; existing whenever he says it does.

Margo McCaffery, 1968

Factors Influencing Perception of Pain



Factors Aggravate or Alleviate the Pain

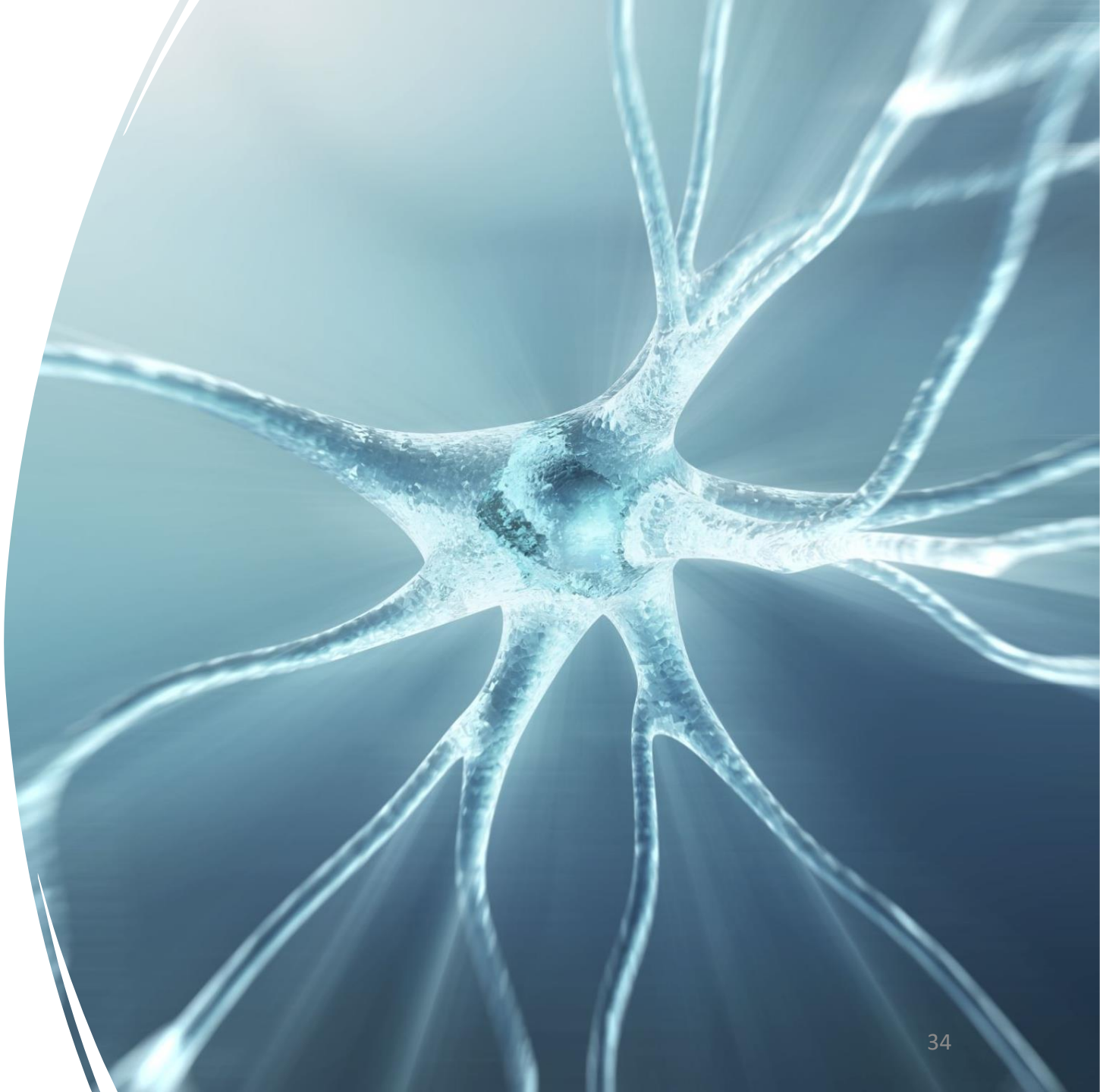
movement, physical therapy, activity, blood draws, depression, sadness, bad news

Analgesics, massage, relaxation, music therapy, heat or cold, nerve blocks

Types of Pain

- Nociceptive:
  - Somatic
  - Visceral

- Neuropathic:
  - Centrally Generated
  - Peripherally Generated



Somatic Nociceptive Pain

- Areas involved
  - bone, joint, muscle, skin, connective tissue
- Description
  - aching
  - throbbing
  - well-localized
- Example: bone metastasis, mucositis, skin lesions

Visceral Nociceptive Pain

- Involves organ tissues: pancreas, liver, spleen, stomach, kidney, gallbladder, urinary bladder, and intestines.

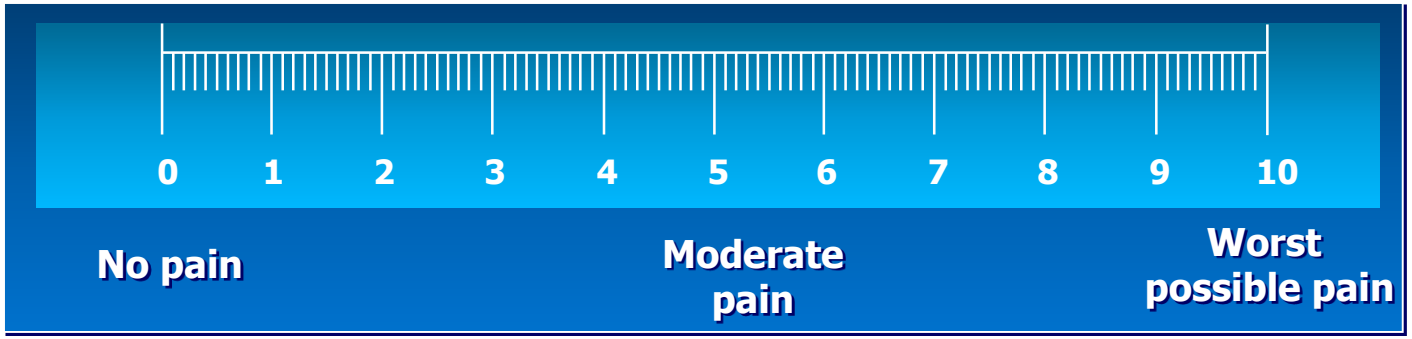
- Description
  - aching
  - intermittent and cramping
  - may be referred to other sites

Neuropathic Pains

- Complex, chronic pain.
- The nerve fibers themselves might be damaged or injured
  - due to damage from surgery, medications, radiation, viruses
  - prolonged exposure to pain stimulus
  - Diabetic neuropathy (peri.) vs spinal cord compression (cent.)
- Described as
  - burning, shooting, shock-like; hyperalgesias/ allodynia

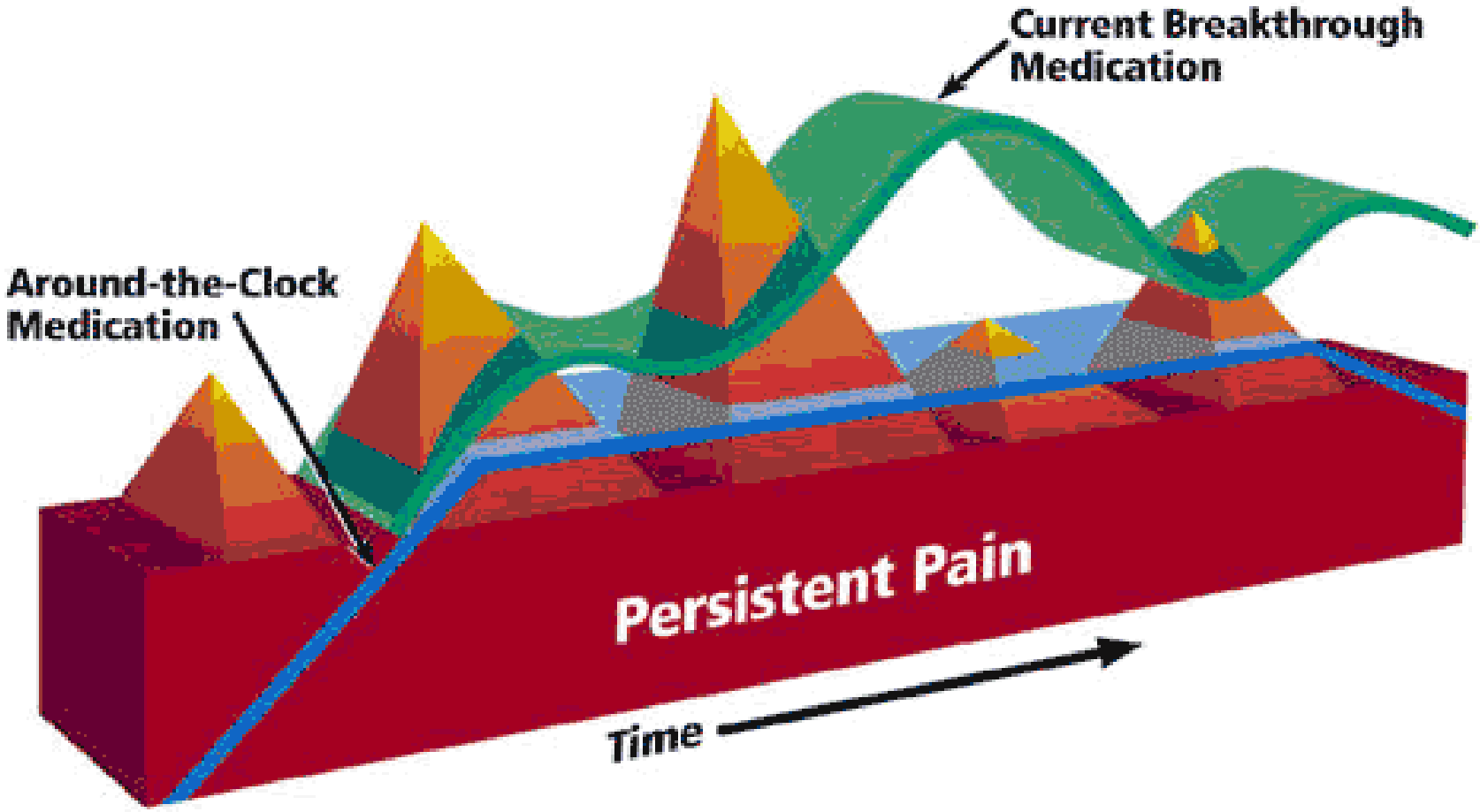
How severe is the pain? (0-10)/mild, moderate, severe?

Numeric Pain Rating Scale



- Most commonly used
- Patients rate their pain on a 0-10 or 0-5 scale with 0 being no pain at all and 5 or 10 being the worst pain imaginable

Constant or Intermittent?



DURATION: ACUTE PAIN

Presentation: characterized by help-seeking behavior such as crying and moving about in a very obvious manner

Cause: definite injury or illness

Signs/symptoms: Sympathetic over-activity: tachycardia, pallor, hypertension, sweating, grimacing, crying, anxious, pupillary dilation

Example: trauma, surgery, or inflammation

DURATION: CHRONIC PAIN

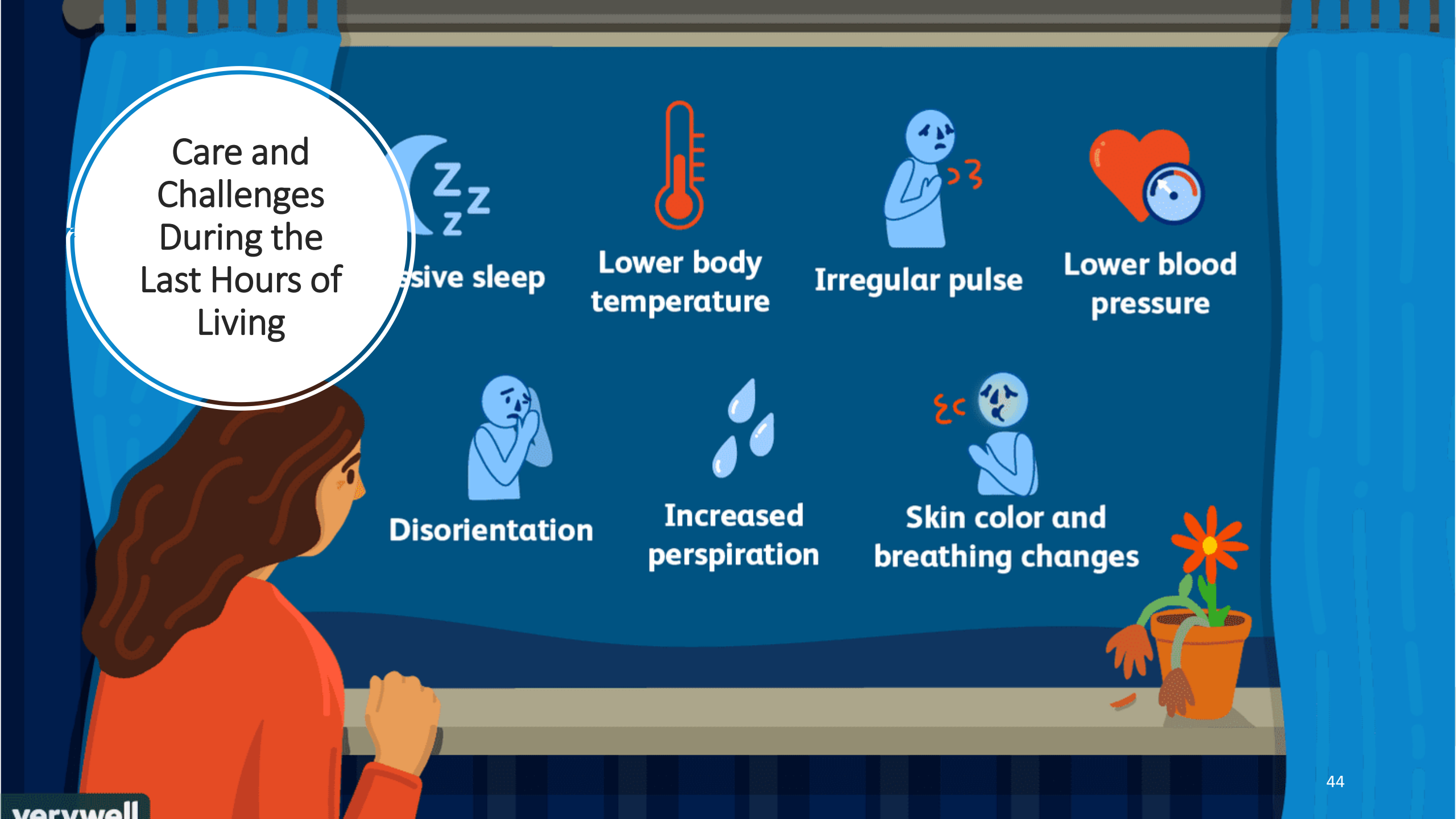
- ***Presentation:*** Patients may not show signs of distress seen in acute pain
- ***Cause:*** chronic pathological process
  - Under-treatment of acute pain can lead to changes in the central nervous system that result in chronic pain
- ***Signs/symptoms:***
  - Gradual onset
  - Continues and may become progressively more severe
  - Patient may appear depressed and withdrawn
  - Usually, no signs of sympathetic over-activity

Impact of Unrelieved Pain

- Physiological
- Psychological
- Economic

Pain Management

- Pharmacological
- Non-Pharmacological


Care and Challenges During the Last Hours of Living
ssive sleep
Lower body temperature
Irregular pulse
Lower blood pressure
Disorientation
Increased perspiration
Skin color and breathing changes
verywell

- Due to cultural perceptions of death as a taboo, there is a general avoidance of advance care planning conversations.
- Planning for EoL care is not common due to strong prohibitions against talking about death, which is considered highly distressing and/or associated with the fear that death talk will accelerate death.
- Dying is an Individual Experience

Signs & Symptoms of Imminent Death

Physical Symptoms

Confusion, delirium
Drowsiness, sedation
Death rally
Weakness/fatigue
Restlessness, agitation
Fever
Decreased oral intake
Decreased urinary output

- Incontinence
- Bowel changes
- Cardiac changes
- Respiratory changes
- Mottled and cold extremities

Changes in Perception

Hearing and vision may deteriorate

Always assume patient can hear

Decreasing level of consciousness

Usually slowly progressive

Expected: do not evaluate for response to painful stimuli

Continue: plan of care for pain and symptoms

Changes in Perception - continued

Confusion and mild agitation

Assess for potential causes

Provide orientation cues

Calm, supportive environment

Delirium

Assess for cause

- Often organ system failure and/or medications

If cannot reverse cause, treat with antipsychotic medication (e.g., Haloperidol)

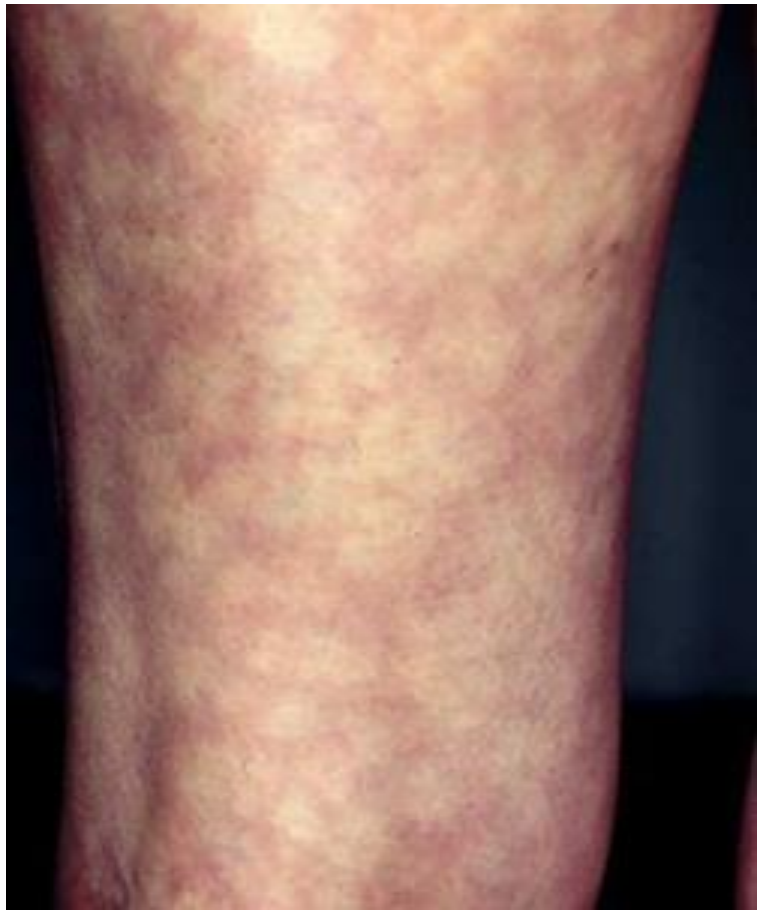
Cardiovascular Changes

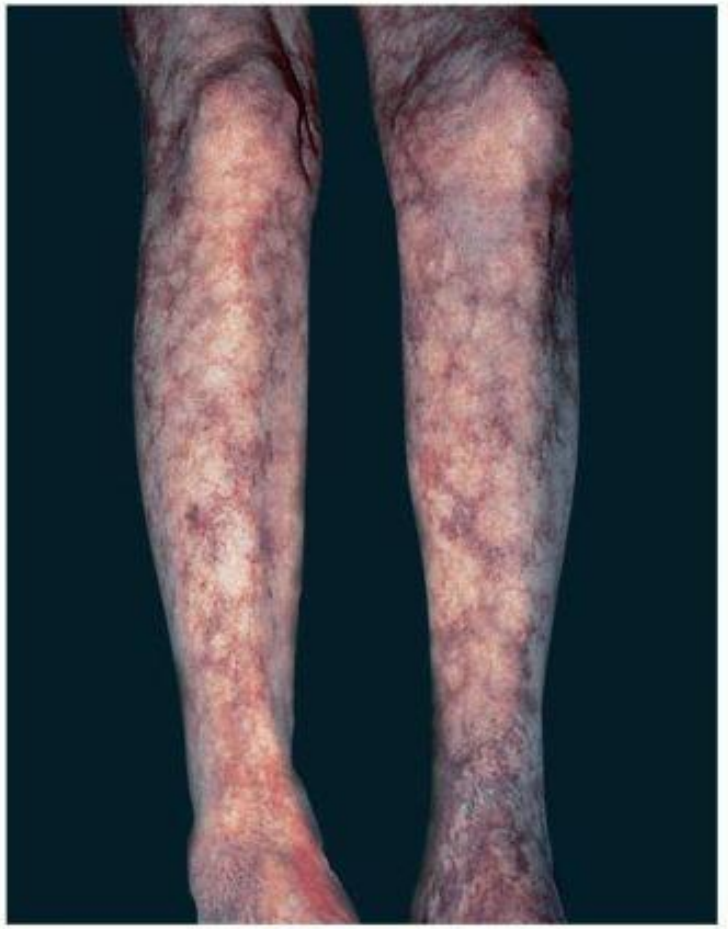
Heart rate

- Early stages: increase as body tries to compensate for decreased blood volume
- Later stages: both heart rate and BP decrease

Decreased circulation

- Skin becomes cool, clammy, mottled
- Core body temperature does not decrease
  - Note: Heavy layering of blankets may cause agitation





This is a picture of mottling that occurs as the body loses circulation.

Respiratory Changes

- **Dyspnea**
  - Assess cause – treat if possible
  - Opioids may be very helpful
  - Oxygen rarely helpful
- **Cheyne-Stokes breathing pattern**
  - Alternating periods of apnea followed by rapid breathing
  - Likely due to abnormal brain stem response to carbon dioxide
- **Agonal breathing**
  - breathing is shallow with long periods of apnea

Interventions

Reposition patient	Short-term Trendelenburg if not uncomfortable
Diuretics	
Discontinue artificial fluids	
Mucolytics for thick secretions	
Suctioning is rarely helpful at end-of-life	
Anticholinergics (imminent death only)	Evidence on effectiveness in inconclusive
Mouth care important	

Renal System Changes

Decreased kidney function

- Due to decreased cardiac function
- Leads to decreased output and concentrated urine
- Often do not tolerate artificial fluids
- Often an imminent sign of death when urinary output ceases

Urinary incontinence

- Sphincters relax as death nears
- Use incontinence pads and good skin care
  - Use catheter if improves comfort

Weakness and Fatigue

Generalized weakness, fatigue

Swallowing may become difficult

- Food and fluids may do harm at this time
  - Aspiration
  - Fluid overload
- May need different route for medications

Family Dilemmas

- How long will my loved one live?
- Should we call the family to come?
- How will I know when *it* is close?

Common Family Concerns

- Is my loved one in pain; how would we know?
- Aren’t we just starving my loved one to death?
- Should I/we stay by the bedside?
- Can my loved one hear what we are saying?
- What do we do after death?

Nearing Death Awareness Themes

- Describing a place
- Talking to someone who is not alive
- Knowledge when death will occur
- Choosing time of death
- Needing reconciliation
- Talk of going on a trip
- Being held back
- Symbolic dreams

Supporting the Family

- **Preparation**
  - Discuss/show signs & symptoms of dying
  - Reinforce teaching with information in writing
  - Funeral planning
- **Being "present" with them**
  - Sitting at bedside
  - Allowing silence
  - Life review
  - Touch, as acceptable to the patient/family

Assist with Completion of “The Five Things” for Relationship Completion

- “I love you”
- “Thank you”
- “Forgive me”
- “I forgive you”
- “Good-bye

Care at the Time of Death

- Death evaluation/pronouncement
- Expressions of sympathy to family
- Bathing of body, according to culture
- Final good-byes by family
- Transportation of body, according to culture
- Rigor mortis 2-4 hours after death

Care Following Death

Ongoing bereavement support

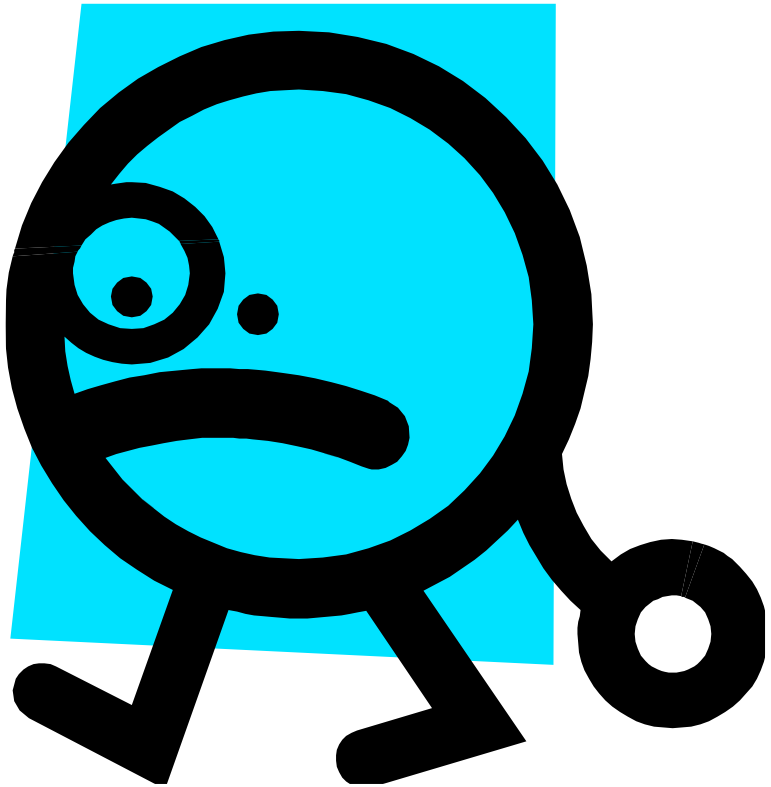
Encourage to accept assistance

- Handling calls
- Food preparation
- Funeral/memorial service arrangements

Destroy medications if needed

Personal Awareness & Self-Care

- Unchecked strong emotions negatively impact quality of care
  - Under- or over-involvement
  - Burnout




QUESTIONS