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Primum non nocere

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The background features a large, light blue circular logo for Western Medical Training Center. The logo contains a caduceus (a staff with two snakes) and the text "WESTERN MEDICAL TRAINING CENTER INC." around the top and "W.M.T.C." at the bottom. The main text of the slide is overlaid on this logo.

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Nutrition and Hydration
For the Hospice Patient

Goal

- To effectively and competently examine the role of artificial nutrition and hydration or ANH as it is often referred to as in the terminally ill patient.



Objectives

- Define the role of nutrition and hydration in the hospice patient
- List burdens and benefits of continuing, withdrawing or withholding nutrition and/or hydration
- Describe symbolism of food and water
 - Issues for family members and caregivers
- Identify ethical issues regarding nutrition and hydration in the hospice patient

Dying Process

- Why do the dying lose their appetite?
 - Not wanting to eat/drink may signify the body is losing function
- Disease process causing body to shut down
 - Not the lack of eating/drinking
- Result: Most patients will:
 - Be unable to take food/fluids by mouth
 - Be uninterested in eating/drinking
 - Experience weight loss

Palliative Care

- "The focus is not on death but on promoting the most compassionate and positive experience for the living: for the resident, family and loved ones sharing in the experience."



Hospice Care

- Palliative or "comfort" care for terminally ill
- patients and their families
- Patient-focused
- Patient guides the care provided by the hospice team
- Focuses on relief of pain and other symptoms
- Promotes the highest quality of life for the patient and family

General Impressions

- Among general public and non-hospice medical professionals
 - Not eating and drinking during the dying process would be a terrible way to die
- Among hospice professionals
- A lack of food and fluid does not contribute to suffering among the dying
 - "Might actually contribute to a comfortable passage from life"

Definition

- Artificial nutrition and hydration (ANH)
 - Provision by tube of a chemically balanced mix of nutrients and fluids
- Two modes of delivery:
 1. Enteral (tube) feeding
 - Delivered via tube into the digestive tract
 2. Parenteral (primarily IV) feeding
 - Delivered via catheter into the blood stream

Enteral (Tube) Feedings

- Nasogastric (NG) tube
 - Stomach via nasal passage
-
- Gastronomy (PEG) tube
 - Through wall of abdomen



Burdens of Enteral (Tube) Feedings

- NG tube - stomach via nasal passage
 - Tubes can traumatize and erode the lining of the nasal passage, esophagus, stomach or intestine
 - Can cause dysphagia/difficulty swallowing
 - Insertion can be frightening, cause gagging, agitation
 - Exacerbation of nausea, vomiting and diarrhea
 - Regurgitation resulting in aspiration

Burdens of Enteral (Tube) Feedings

Continued

- PEG tube - via wall of the abdomen
 - Surgical complications
 - Skin infection
 - Often requires replacement



Parental (IV) Feedings

- Total parenteral nutrition (TPN)
 - Formula is infused via central venous catheter
- Infusion
 - Water, saline or glucose solutions are delivered via a peripheral or central line

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Burdens of Parenteral (IV) Feedings

- TPN formulas can cause:
 - Inflammation
 - Occlusion
 - Increased risk of infection
 - Fluid overload
- Tumor growth
 - Decrease in pleasure of eating (If the patient can eat)

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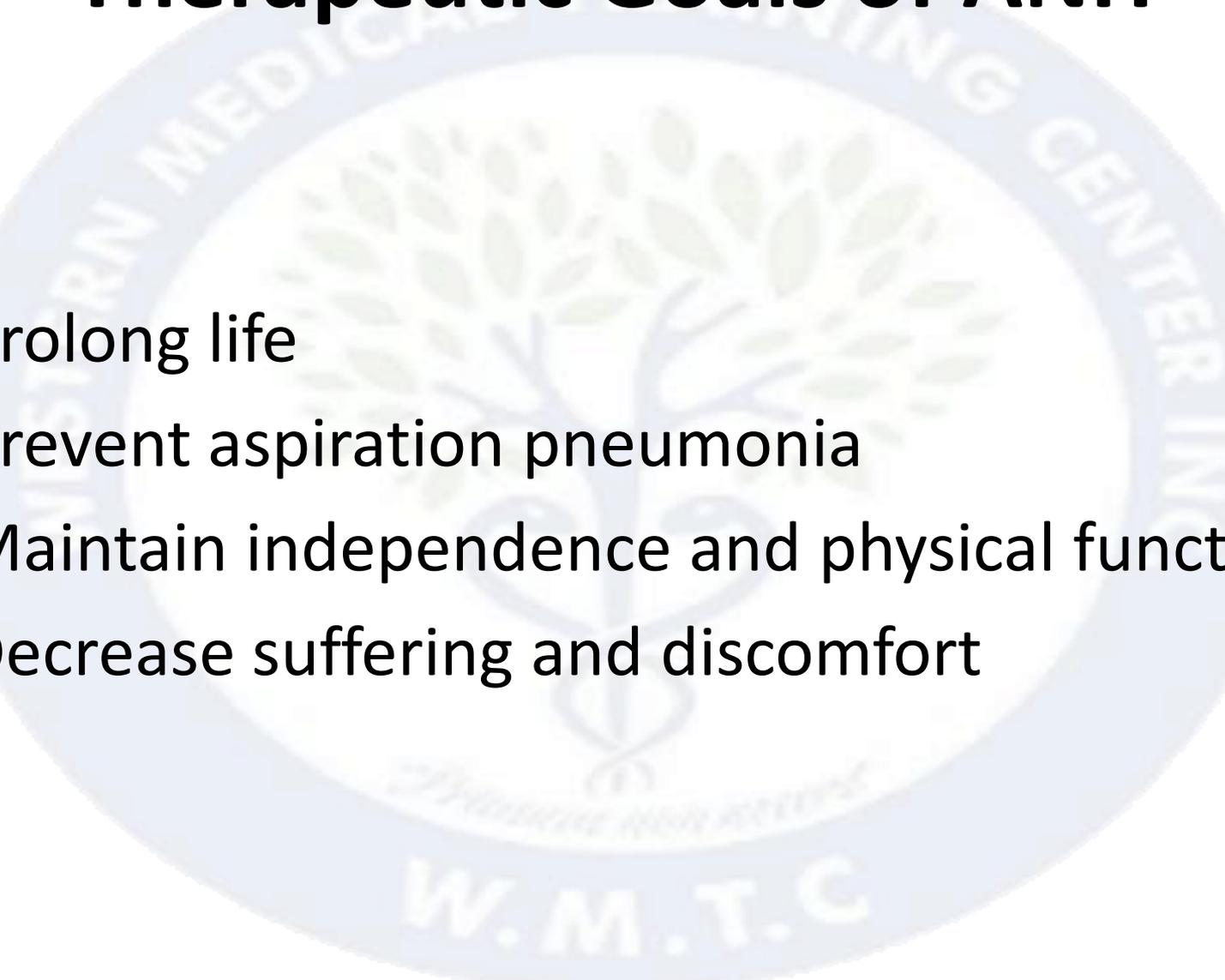
Burdens of Parenteral (IV) Feedings *cont...*

- **Intravenous:**
 - Uncomfortable
 - Infiltration
 - Inflamed or infected skin
 - Fluid overload - worsens edema
 - Increases respiratory secretions resulting in breathing difficulties



Therapeutic Goals of ANH

- Prolong life
- Prevent aspiration pneumonia
- Maintain independence and physical function
- Decrease suffering and discomfort



ANH Does Not

- Prolong life in most patients with life-limiting, progressive diseases
 - May actually increase mortality as a result of complications from tube placement
- Protect against aspiration pneumonia
 - May actually increase the risk
- Enhance physical function or independence
 - May actually increase dependence
- Decrease suffering/discomfort at the end of life
 - May actually increase discomfort both physically and socially/emotionally

Fears of Withholding ANH

- Withholding ANH will increase patient's suffering
- Patient will "starve to death"
- Myth: Without it:
 - A long and painful death
- Truth: Without it:
 - A more comfortable death
- The need for nutrition and hydration differs in persons in good health versus those who are dying

Nonverbal/Nonresponsive Patients

- Unable to report feeling full, they may experience:
 - Abdominal bloating
 - Cramps
 - Diarrhea
- Confused patients
 - May become anxious
 - Pull out the tube
 - May lead to severe bedsores

Dehydration Symptoms

- Most prevalent - "Thirst" and dry mouth
 - Relieved through small sips of water, ice chips and good mouth care
- These symptoms are not associated with dehydration in terminally ill patients:
 - Headache, nausea, vomiting, cramps
- These symptoms are related to the disease process

Non-Eating Symptoms

- Hospice patients do not suffer without nourishment and are **unlikely** to experience pain related to a lack of nourishment
 - Studies show that the body responds to a lack of food by increasing the production of natural pain relievers (endorphins)
 - Re-introduction of even a small amount of food/sugar (such as that found in IV fluid) can bring back the sensation of hunger and stop the production of endorphins

Physical Benefits of Withholding ANH

- Decreases urine output
- Diminishes dysphagia and vomiting
- Reduces edema, ascites and abdominal pressure
- Decreases possibility of developing aspiration pneumonia



Physical Benefits of Withholding ANH

continued

- Prevents fluid overload
 - End-stage patients suffer Less from congestion. coughing and the "drowning" sensations that accompany tube feedings
- Eliminates the physical irritation associated with feeding tubes

Psychosocial Benefits of Withholding ANH

- For the patient:
 - Elimination of agitation/discomfort (re: feeling trapped) brought about by use of tubes
 - The pleasure of eating and human contact if feeding is necessary
- For the family:
 - Elimination of technical barriers
 - Easier to provide comfort care and be close to their loved one during the dying process

Most Importantly!

"ANH takes away the patient's choice to stop intake of food and fluid when appropriate for them as related to the natural progression of their terminal disease. "

Honey Miller, RN
Hospice Nurse for 7 years

Ganzini Study

- 2003 study of hospice nurses in Oregon
- Ranges were:
 - 0 (a very bad death) to 9 (a very good death)
- The median score for "quality of death" for those who chose to forgo food and fluids at the end of life was 8.

Survey

- Hospice nurses' perceptions regarding nutritional support for terminally ill cancer patients
 - 30 hospice nurses
 - In a home-based Florida hospice
 - Caring for a census of 300 patients
 - Completed a questionnaire on their experience related to nutrition and dehydration
- Results were consistent with the literature



Survey Results

Questions

1. The main reason for poor eating?

– Poor appetite 77%

3. What would the benefits of more aggressive nutritional support?

– Do more harm than good 95%

4. Does malnutrition seem painful

– Not painful 72%

Survey Results *continued*

Questions

5. Who and how much concerned overweight loss?

- Patient report “very concerned” 26%
- Family report “very concerned” 77%

10. In patients dying with dehydration, how is quality of life?

- Don’t suffer much 77%
- Fewer problems with secretions 65%

Survey Conclusion

- Artificial nutrition and hydration does not provide comfort care for dying patients. Experience and available scientific information have shown that death without ANH is natural and pain free.



Is ANH Ever Appropriate for the Hospice Patient?

- Yes!
 - If it is the patient's wish
 - Requesting to continue AHN treatment
 - Considerations
 - Cultural or religious beliefs

"Food and fluid administration beyond the specific requests of patients may play a minimal role in providing care to terminally ill patients."

Professional Concerns

- Professional caregivers
 - Nonmalfeasance
 - "First, do no harm"
- **Focus is on the patient's:**
 - Wishes
 - Desired comfort level



Symbolism of Food and Fluid

- Food + Water = Life
 - Fear is deeply rooted in the belief that life requires food and fluid for comfort
- If you don't feed = You don't care
 - Feeding expresses the essence of care and compassion
 - Feeding communicates basic human and professional values



Symbolism of Food and Fluid, *cont...*

- Providing sustenance is one way we can ignore the reality that the patient is dying
 - "If I can keep him eating then he can't really be dying"
 - Often our sense of powerlessness pushes us to want "do more" for the patient
 - Can help to manage feelings of impotence, guilt, fear, anger and impending loss

Practice awareness: Whose needs are we trying to meet?

Remember:

- *"Artificial nutrition and hydration should never be confused with ordinary food and water; they are very different, and the experience of the person receiving them is also different."*

Start Where the Patient Is

- If the patient can eat or drink
 - Provide Assistance
 - Teach family
 - Safe feeding techniques
 - How to honor cues from patient
- •When no longer appropriate
 - Teach family members other ways to show love and support

Interventions

- Assess for treatable causes of decreased appetite
 - Oral thrush
 - Nausea and vomiting
 - Metabolic disturbances
- Provide dietary counseling for patient
 - Smaller plates and portions
 - Eat whenever desired and allow favorite foods
 - Lift dietary restriction (i.e. low salt. ADA)
 - Avoid strong smells, spices, hot foods
- Provide dietary counseling for family
 - Need for less food
 - Lifting of dietary restrictions

Ethics and Advance Directives

- •The U.S. Supreme Court and leading medical organizations agree that ANH constitutes medical treatment that patients can accept or refuse, similar to:
 - ventilators
 - Surgery
 - Antibiotics
- Important to:
 - Have an advance directive and know state laws



Questions to Ask

- Is it intrusive and burdensome?
- Is it comforting and beneficial?

To the Patient's Quality of Life



Alamy CT3PAN

Withholding Food and Fluid

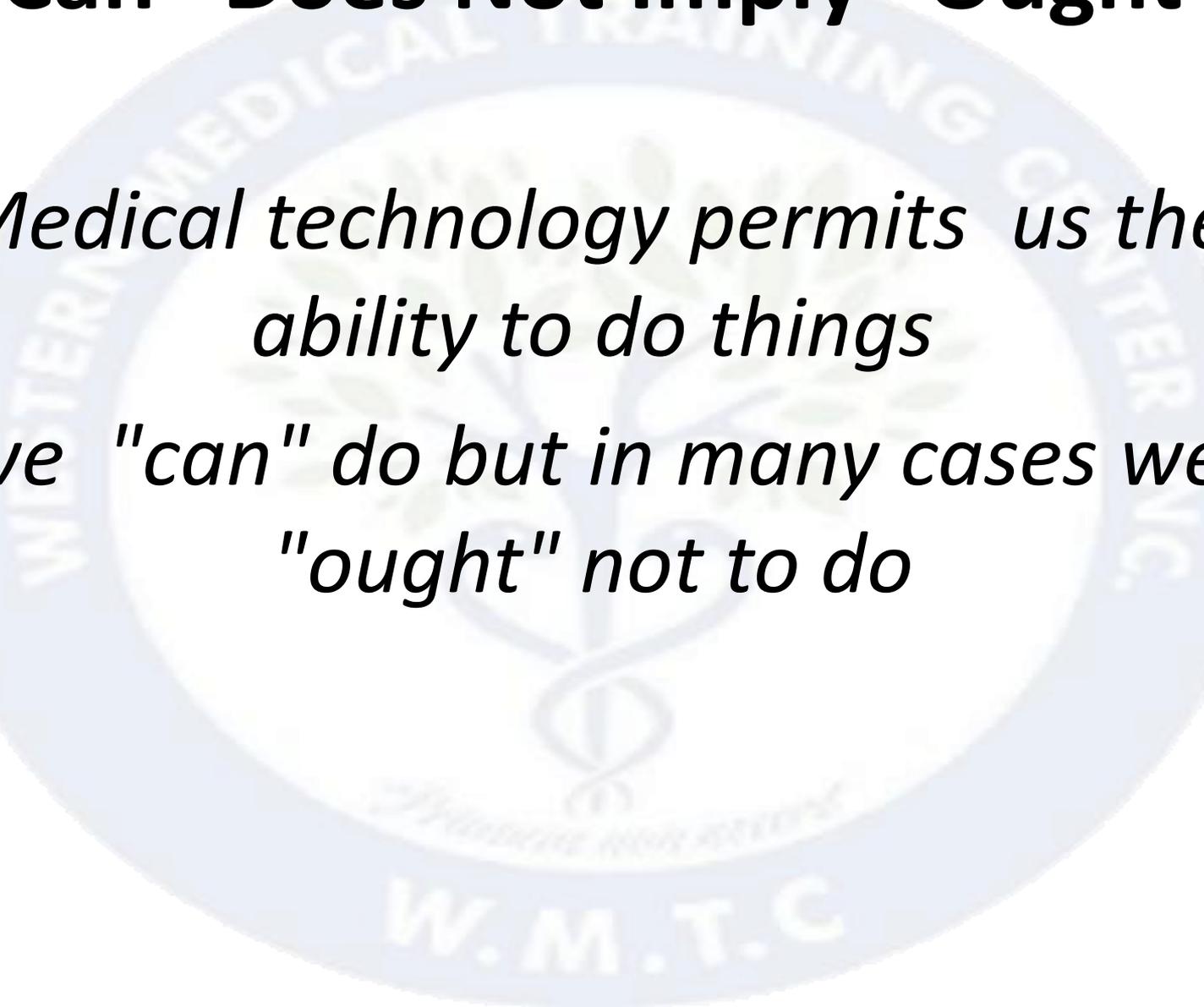
- If the patient is alert and oriented:
 - Discuss patient's values and goals for care
- If unconscious, unresponsive or confused
 - Refer to advance directive - written or verbal
 - Discuss the desires of the family
- Knowledge of the disease process
 - Provide effects of artificial feeding and fluids on the patient

Remember:

Reassure family members that their loved one is not in pain or experiencing hunger or thirst-related suffering!

"Can" Does Not Imply "Ought"

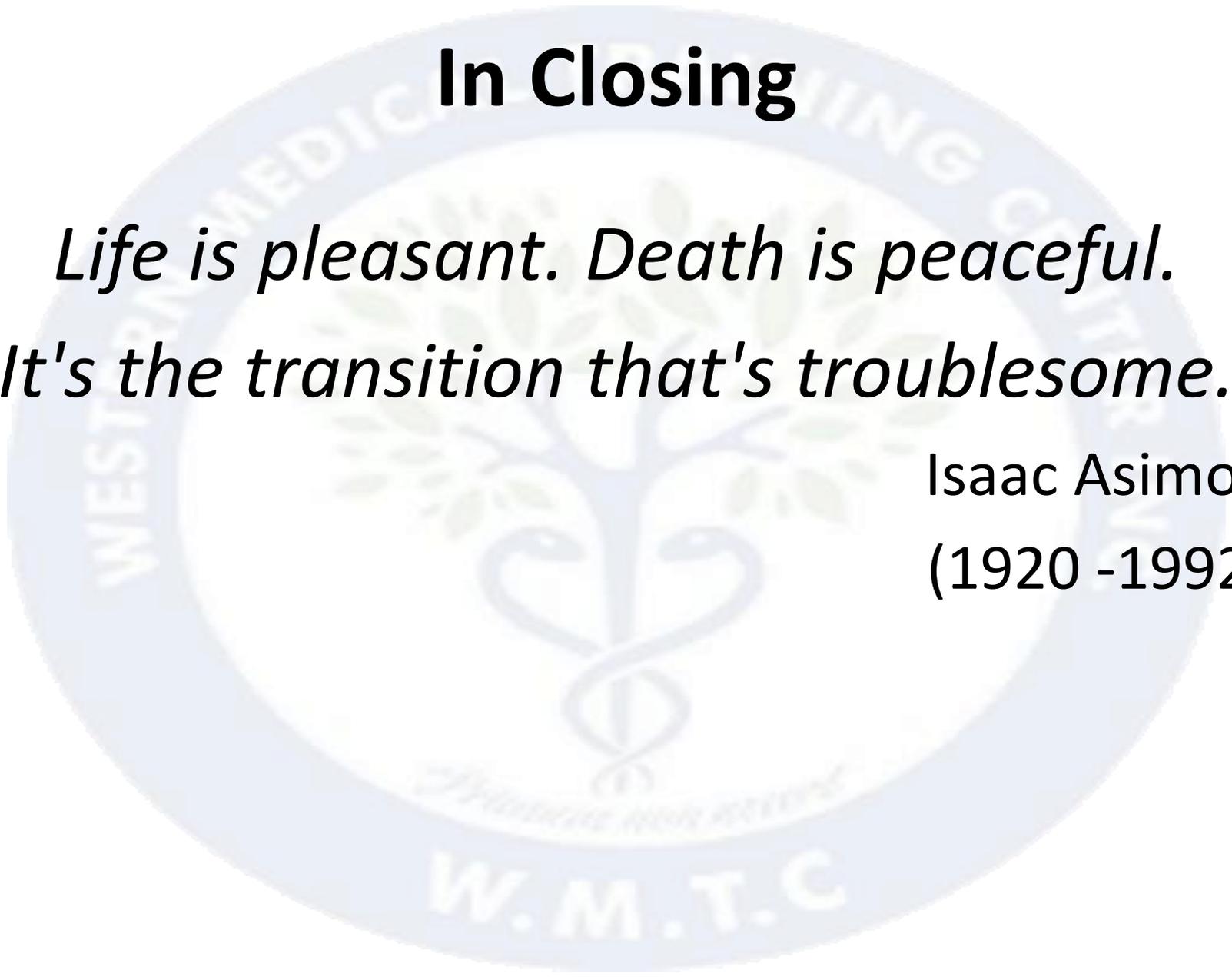
*Medical technology permits us the
ability to do things
we "can" do but in many cases we
"ought" not to do*



In Closing

*Life is pleasant. Death is peaceful.
It's the transition that's troublesome.*

Isaac Asimov
(1920 -1992)



In Review

- Defined the role of nutrition and hydration in the terminally ill patient
- Listed the burdens and benefits of continuing, withdrawing or withholding nutrition and/or hydration
- Described the symbolism of food and water and the resulting issues for family members and caregivers
- Identified ethical issues regarding nutrition and hydration in the terminally ill patient

Questions?



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Thank you for your attention!

