

# Ethical Considerations and Quality of Life

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Continuum of Care

# HISTORY

- Continuum of Care and HDR consults with a patient in crisis
  - Inpatient and needing a quick decision
  - Team disagrees with guardians decision
  - Team disagrees with physicians' recommendation
  - Client's preference does align with medical recommendations
- Development of handouts to help to facilitate team dialogue
  - Before crisis develops

# An Approach to Using the Pamphlet “Feeding Tube - Questions & Considerations for Healthcare Decision Makers”

- The questions are designed to stimulate dialogue within the team.
- There are no universally correct answers.
- Every individual is different.
- The physician may be able to answer some of the questions.
- “I don’t know” is a valid answer.

# “On Tube Feedings”

- Dysphagia
- Feeding Tubes- Types/Descriptions
- Immediate and Long-term Risks & Complications
- Bolus Feedings
- Continuous Feedings
- Tube Care
- Oral Care and Oral Hygiene
- Long Term Implications

# Team Approach

- The guardian makes the final decision.
- The team supports the guardian in making an informed decision.
- The importance of Informed Consent
- Gather input from all parties involved-MD, RN, SLP, case managers, care givers and family.
- Respect for the Individual's preferences.
- Consideration of the individual's health, fatigability, safety, nutritional status and quality of life.

# Ethical Considerations

- Risk versus Benefit
- What are the alternatives?
- Quality of Life
- Potential complications
- Cultural implications for the patient and family
- When the guardian makes a decision, the team should work together to best help support the individual in maximizing their quality of life

# Clinical Considerations

- Gastrointestinal Disease
  - GERD
  - Constipation
  - GI Motility
- Pulmonary Status
  - Chronic Micro-Aspiration over a lifetime
  - Recurrent Pneumonia
  - Chronic Lung Disease

# Clinical Considerations

- Neurologic
  - Seizures
  - Spasticity
  - Gastroparesis
  - Dependent Feeders
- Saliva Management
  - Can the Individual Manage Their own Secretions?
- Oral Hygiene
  - Oral Hygiene Plan
  - Changes in Oral Flora Secondary to NPO status



# Clinical Considerations

- Positioning
  - Scoliosis
  - Postural Tone
  - Sleep
- Behavioral Challenges
  - Pulling out the tube
  - Rumination
  - Food Seeking
  - Pica

# RESOURCES

- SAFE clinic – Elizabeth Ceysens at 505-272-0285
- Feeding Clinic – Carrie Tingley Hospital – 505-272-4511
- Continuum of Care – 505-925-2350 or 877-684-5259
- DDS/D/Clinical Services Bureau – 505-841-2907
- DDS/D/IAA Unit – Christine Wester at 505-841-5529
- Individual's IDT members (PCP, Nurse, SLP, PT, OT)