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

• DDSD/Clinical Services Bureau – 505-841-2907

• DDSD/IAA Unit – Christine Wester at 505-841-5529

• Individual’s IDT members (PCP, Nurse, SLP, PT, OT)