



QR code for mobile view

- Inclusion criteria:**
- When currently admitted to an inpatient unit and:
    - Parent, caregiver, or patient chooses to pursue comfort focused End of Life Care
    - Patient's clinical status has changed to life expectancy of a few hours to a few days
- Exclusion criteria:**
- Patient in PICU, CICU, or ICN
  - Any patient with an active police investigation

**Child at or near end-of-life and do not attempt resuscitation (DNAR) status has been confirmed with family/patient**

**Evaluate and Diagnosis**

- Update patient's primary care provider
- Consult Palliative Care Team (PaCT)
- Engage PaCT for planning and co-management

**Establish Customized Care Plan with Patient/Family**

- Discuss** physical and environmental expectations
- Identify** family requests and needs
- Determine** staffing needs  
*Provide end-of-life resources to family*

**End of Life Huddle**

- Share family care plan and goals with multidisciplinary care team
- Answer staff concerns and address any staff distress
- Identify and assign care team roles  
*End of Life Huddle Process*

**Discuss**

- Anticipated symptoms (psychological and physical)
- Physical environment considerations (e.g., monitors, lines, tubes, family bed)
- Visitation needs/restrictions

**Identify**

- [Cultural, legal & ethical aspects of care](#)
- Additional family support needs (e.g., sibling support, grandparents)
- Family desire for butterfly cart, memory items, or photography

**Determine**

- Language services involvement
- Tissue/research donation plans (*refer to CMKC policies*)
- Locations of events/rituals
- Other disciplines needed
- Which team members will offer services/support

Implement Customized Care Plan				
<a href="#">Psychological Symptom Management</a>	<a href="#">Pain Management</a>	<a href="#">Respiratory Symptoms &amp; Secretion Management</a>	<a href="#">Nutrition, Hydration, &amp; GI Symptom Management</a>	<a href="#">Fever Management</a>

**Reassess Customized Care Plan**

- Reassess at regular intervals
- Report out during bedside rounds
- Refer to and update *End of Life Huddle Critical Information Note* as needed

**Death**

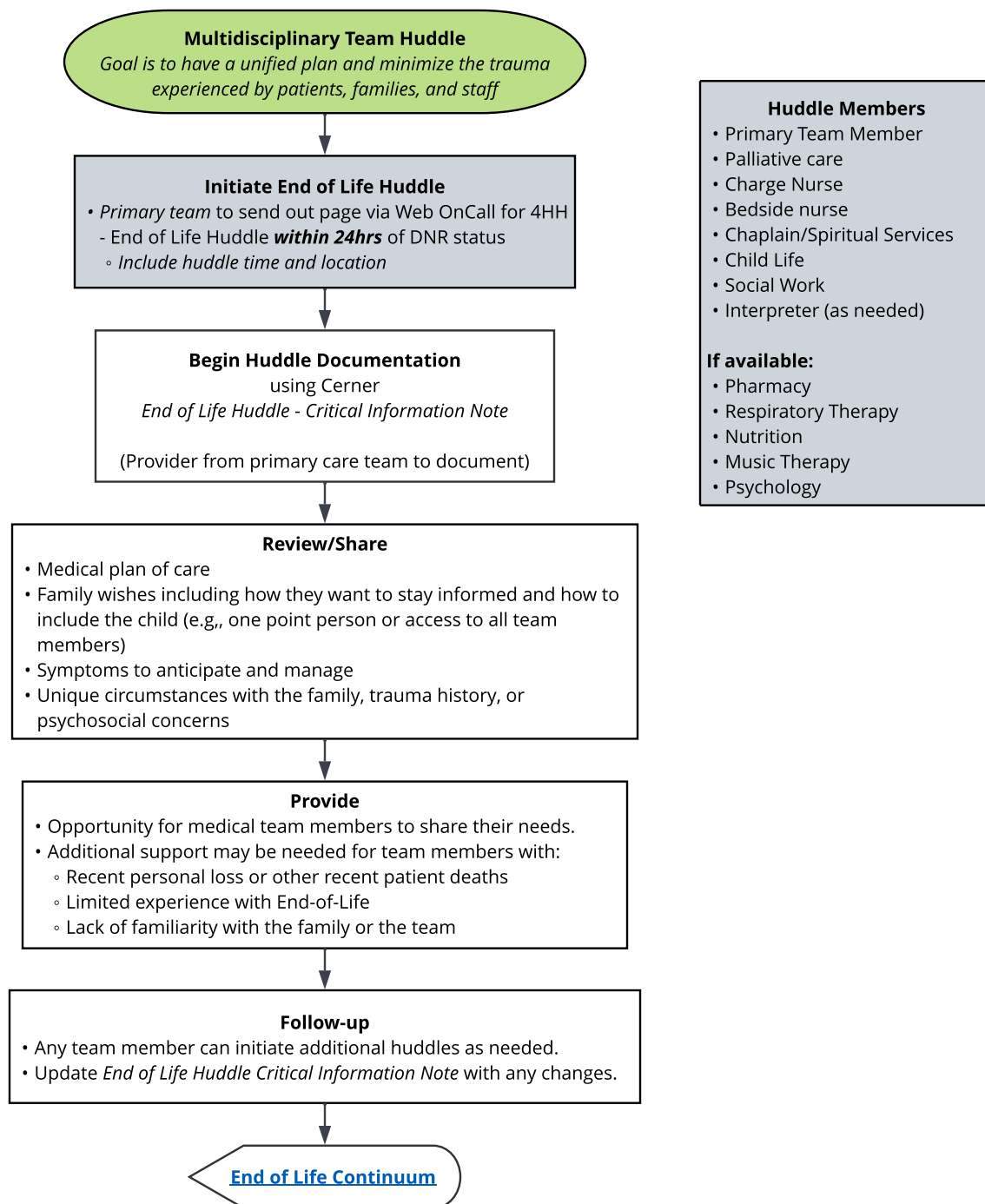
- Pronounce death - Physician**
  - Physician called to bedside to confirm death (assess patient, listen for heart tones x 2 minutes) - *note time of death for documentation*
  - Death confirmed, physician shares "(pt. name) has died"
- Complete death record - Spiritual Services**
- Complete death certificate** (physician will be contacted by health information management): [Missouri, Kansas](#)
- Cancel** upcoming appointments, home health supplies (if any), pharmacy refills - *Nurse Case Manager/Social Work*

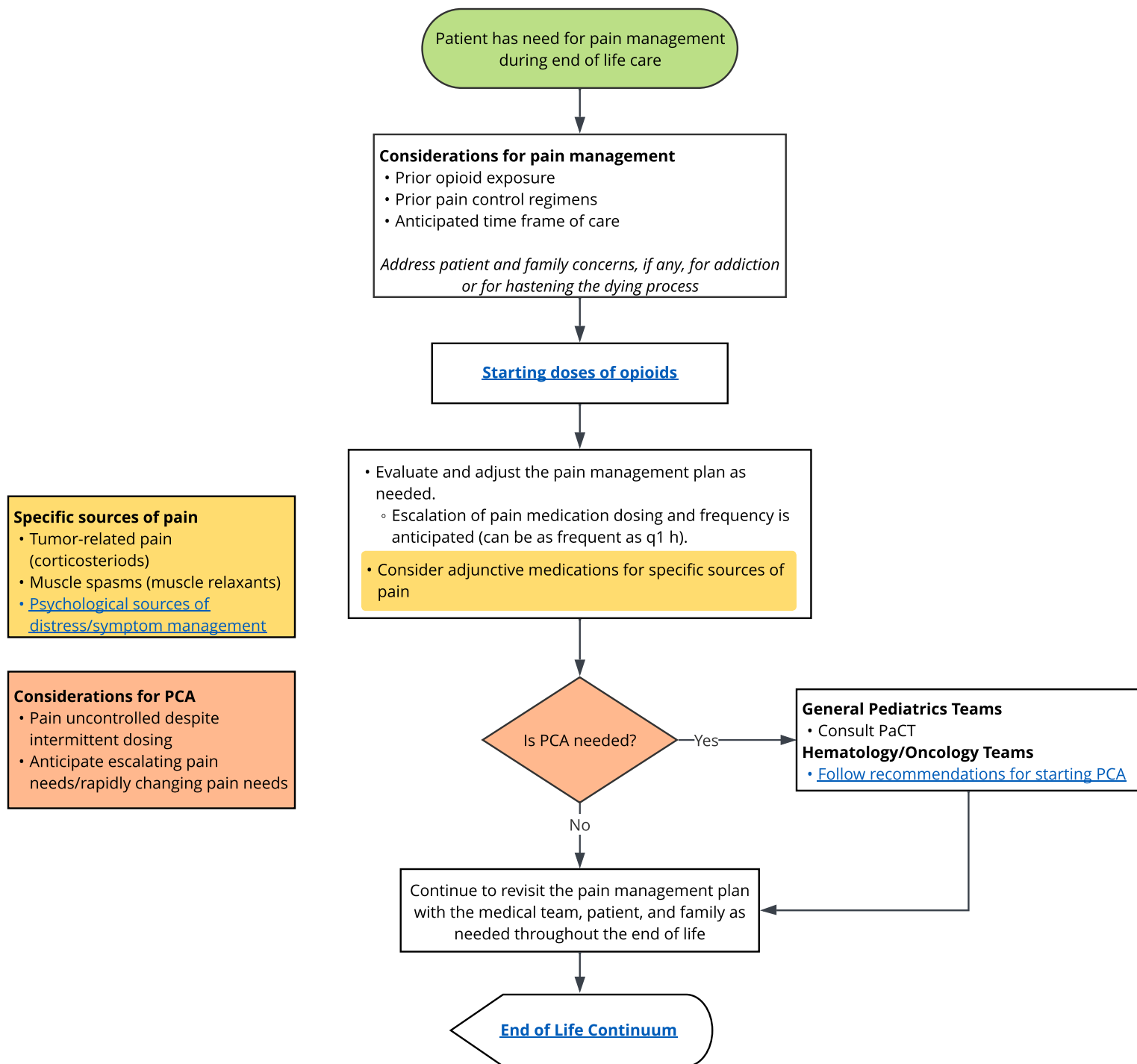
**Family Bereavement Support**

- Ensure** caregiver/family wishes are documented
- Discuss** plan for funeral, photography, organ donation (*Spiritual Services will provide the Everest Funeral Planning brochure*).
- Assess** caregiver/family safety and support system
- Offer** information from the CM [Aftercare Program](#), Courageous Parent Network re: [Bereavement](#).
- Provide** [letter of condolence](#)

**Staff Bereavement Support**

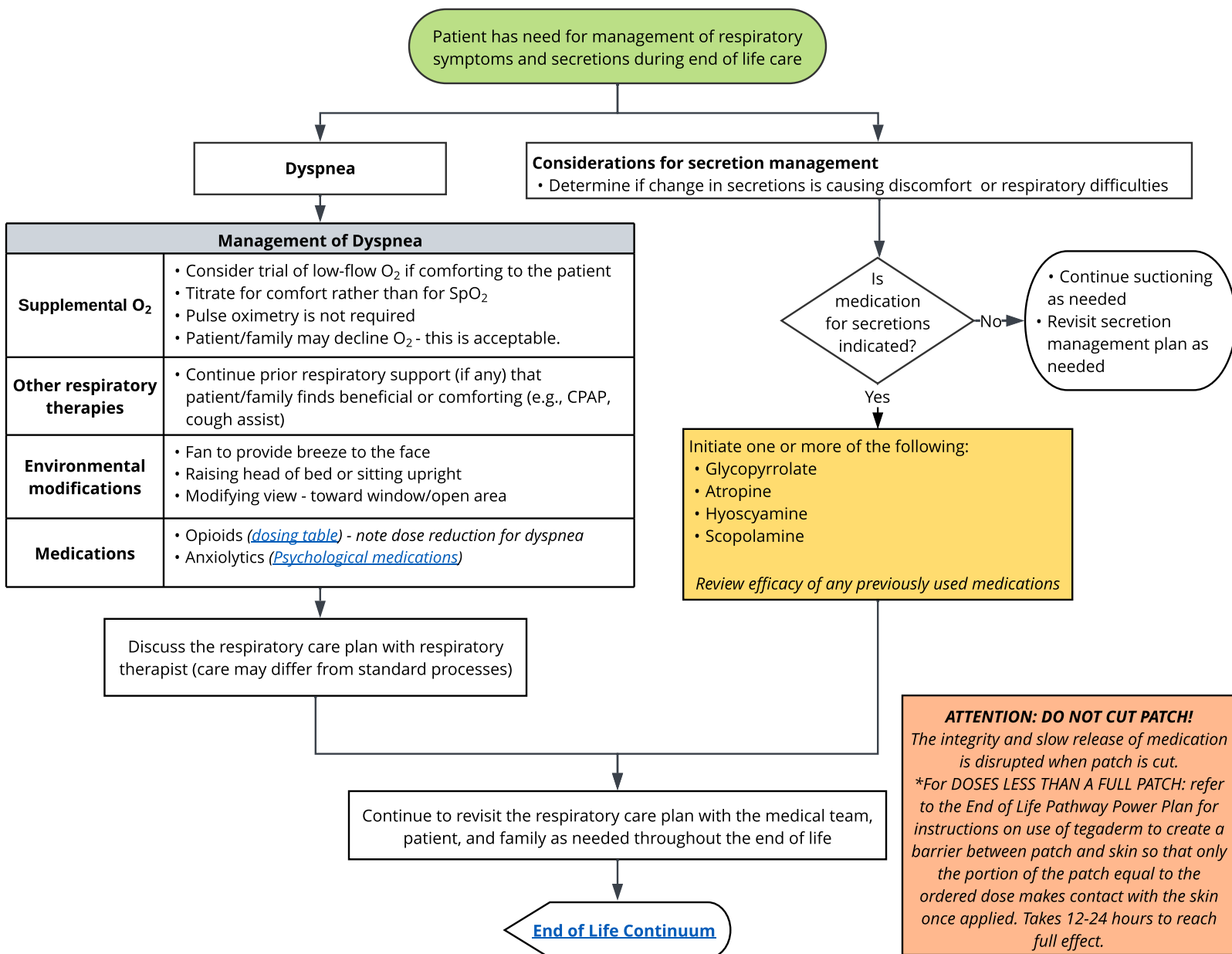
- Pause** to acknowledge patient's passing
- Staff debriefing** - ensure staff are aware of the [Center for Wellbeing](#) and availability for individual or group support
- Visitation or funeral attendance** - discuss with your supervisor





#### Abbreviations:

- PaCT - Palliative Care Team
- PCA - patient controlled analgesia

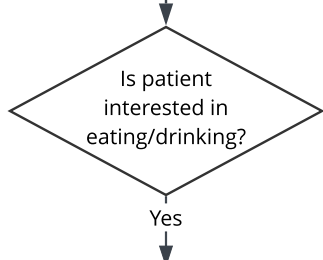


Secretion Management Medications				
Drug	Route	Starting Dose	Max Dose	Additional considerations
Glycopyrrolate	PO	0.04 - 0.1 mg/kg q4h - q6h	1 - 2 mg/dose or 8 mg/day	• Use caution if secretions are thick (may cause mucus plugging)
	IV	0.004 - 0.01 mg/kg q4h - q6h	0.1 - 0.4 mg/dose or 1.2 mg/day	---
Atropine Ophthalmic Drops	Sublingual	1 drop q6h PRN excess secretions	1 drop q4h	• Can be administered even if patient cannot swallow
Hyoscyamine	PO or sublingual	2 - 12 yrs: 0.0625 - 0.125 mg/dose q4h >12 yrs: 0.125 - 0.25 mg/dose q4h	2 - 12 yrs: 0.75 mg/day >12 yrs: 1.5 mg/day	---
Scopolamine	Transdermal patch	1 mo - 2 yo: 1/4 patch 3 yo - 9 yo: 1/2 patch 10 yo - 17 yo: 1 patch	Max dose: 1 patch every 72hrs	• Takes 12 - 24 hours to reach full effect



**Nutrition and Hydration**  
 It is important to understand that as patients approach the end of life, the ability of their body to maintain normal functions is decreased. This includes the drive to eat and the ability to process nutrients that enter the body. As a result, invasive nutritional interventions should be decreased because they can cause more discomfort as patients and their providers transition to comfort-directed care that alleviates symptoms.

Patient has need for nutritional, hydration, and GI symptom management during end of life care

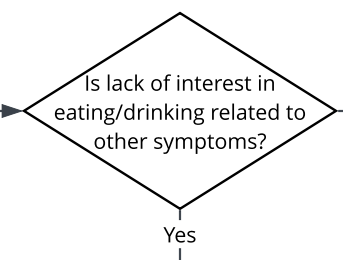


**Patients can PO as tolerated for comfort.**

- Offer small amounts of pts favorite foods rather than larger meals.
- It is expected pt will eat smaller amounts and may prefer softer or liquid food choices.
- Avoid unnecessary dietary restrictions to increase pleasure.

**If patients have difficulty swallowing or are at risk of aspiration:**

- Discuss risks and benefits of eating by mouth with family.



Treatment of **nausea** and/or **constipation**

- Initiating IVF and/or tube feeds not recommended
- For pts already on IVF and/or tube feeds, these may be decreased or discontinued depending on pt/family preferences or in response to change in symptoms
- Resource for caregivers: [Understanding nutritional needs at End of Life](#)

*Loss of appetite and thirst are normal and expected*

**For dry mouth:**

- Provide non-pharmacologic care:
  - Routine mouth cares
  - Mint/plain ice cubes

Continue to revisit nutrition and hydration plan with the medical team, patient, and family as needed throughout the end of life

[End of Life Continuum](#)

**ATTENTION: DO NOT CUT PATCH!**  
 The integrity and slow release of medication is disrupted when patch is cut.  
 \*For DOSES LESS THAN A FULL PATCH: refer to the End of Life Pathway Power Plan for instructions on use of tegaderm to create a barrier between patch and skin so that only the portion of the patch equal to the ordered dose makes contact with the skin once applied. Takes 12-24 hours to reach full effect.

Nausea		Constipation
<p><b>Non-pharmacologic</b></p> <ul style="list-style-type: none"> <li>• Relaxation</li> <li>• Biofeedback</li> <li>• Acupuncture</li> <li>• Aromatherapy</li> </ul>	<p><b>Medications</b></p> <ul style="list-style-type: none"> <li>• Ondansetron: 0.15 mg/kg/dose PO/IV q8h PRN (max 8 mg per dose)</li> <li>• Promethazine: &gt;2 yo: 0.25 mg/kg/dose PO/IV q 6-8h PRN (max 1 mg/kg/24h)</li> <li>• <b>Scopolamine (Transdermal) q72h:</b> 1 mo - 2 yo: 1/4 patch 3 yo - 9 yo: 1/2 patch 10 yo - 17 yo: 1 patch</li> <li>• Metoclopramide: 0.01-0.02 mg/kg/dose IV q4h</li> <li>• Haloperidol: • 0.01 - 0.02 mg/kg/dose PO q30 minutes PRN</li> </ul>	<p><b>Medications</b></p> <ul style="list-style-type: none"> <li>• Lactulose</li> <li>• Polyethylene glycol</li> <li>• Docusate/senna</li> <li>• Methylnaltrexone</li> </ul>