End of Life Continuum

Associated Power Plans: End of Life Pathway, End of Life PCA

Children's Mercy KANSAS CITY | Evidence Based Practice

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

QR code for mobile view

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

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

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

Implement Customized Care Plan

Psychological Symptom Management	Pain Management	Respiratory Symptoms & Secretion Management	Nutrition, Hydration, & GI Symptom Management	Fever Management

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

Contact: EvidenceBasedPractice @cmh.edu

Link to synopsis and references

Last Updated: 7.03.2024

End of Life: Huddle Process

Associated Power Plans: End of Life Pathway, End of Life PCA

Children's Mercy KANSAS CITY | Evidence Based Practice

Multidisciplinary Team Huddle
Goal is to have a unified plan and minimize the trauma experienced by patients, families, and staff

Initiate End of Life Huddle
- *Primary team* to send out page via Web OnCall for 4HH - End of Life Huddle ***within 24hrs*** of DNR status
  - *Include huddle time and location*

Begin Huddle Documentation
using Cerner
End of Life Huddle - Critical Information Note

(Provider from primary care team to document)

Review/Share
- Medical plan of care
- Family wishes including how they want to stay informed and how to include the child (e.g,, one point person or access to all team members)
- Symptoms to anticipate and manage
- Unique circumstances with the family, trauma history, or psychosocial concerns

Provide
- Opportunity for medical team members to share their needs.
- Additional support may be needed for team members with:
  - Recent personal loss or other recent patient deaths
  - Limited experience with End-of-Life
  - Lack of familiarity with the family or the team

Follow-up
- Any team member can initiate additional huddles as needed.
- Update *End of Life Huddle Critical Information Note* with any changes.

End of Life Continuum

Huddle Members
- Primary Team Member
- Palliative care
- Charge Nurse
- Bedside nurse
- Chaplain/Spiritual Services
- Child Life
- Social Work
- Interpreter (as needed)

If available:
- Pharmacy
- Respiratory Therapy
- Nutrition
- Music Therapy
- Psychology

End of Life: Pain Management

Associated Power Plans: End of Life Pathway, End of Life PCA

Children's Mercy KANSAS CITY | Evidence Based Practice

Patient has need for pain management during end of life care

Considerations for pain management
- Prior opioid exposure
- Prior pain control regimens
- Anticipated time frame of care

Address patient and family concerns, if any, for addiction or for hastening the dying process

Starting doses of opioids

- Evaluate and adjust the pain management plan as needed.
  - Escalation of pain medication dosing and frequency is anticipated (can be as frequent as q1 h).
- Consider adjunctive medications for specific sources of pain

Specific sources of pain
- Tumor-related pain (corticosteriods)
- Muscle spasms (muscle relaxants)
- Psychological sources of distress/symptom management

Considerations for PCA
- Pain uncontrolled despite intermittent dosing
- Anticipate escalating pain needs/rapidly changing pain needs

Is PCA needed?

Yes

General Pediatrics Teams
- Consult PaCT

Hematology/Oncology Teams
- Follow recommendations for starting PCA

No

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

End of Life Continuum

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

End of Life: Respiratory Symptoms & Secretion Management

Associated Power Plans: End of Life Pathway, End of Life PCA

Children's Mercy KANSAS CITY | Evidence Based Practice

Patient has need for management of respiratory symptoms and secretions during end of life care

Dyspnea

Management of Dyspnea

Supplemental O_2	• Consider trial of low-flow O_2 if comforting to the patient • Titrate for comfort rather than for SpO_2 • Pulse oximetry is not required • Patient/family may decline O_2 - this is acceptable.
Other respiratory therapies	• Continue prior respiratory support (if any) that patient/family finds beneficial or comforting (e.g., CPAP, cough assist)
Environmental modifications	• Fan to provide breeze to the face • Raising head of bed or sitting upright • Modifying view - toward window/open area
Medications	• Opioids (*dosing table*) - *note dose reduction for dyspnea* • Anxiolytics (*Psychological medications*)

Discuss the respiratory care plan with respiratory therapist (care may differ from standard processes)

Considerations for secretion management

• Determine if change in secretions is causing discomfort or respiratory difficulties

Is medication for secretions indicated?

No → • Continue suctioning as needed
• Revisit secretion management plan as needed

Yes

Initiate one or more of the following:
• Glycopyrrolate
• Atropine
• Hyoscyamine
• Scopolamine

Review efficacy of any previously used medications

Continue to revisit the respiratory care 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.*

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

Contact: EvidenceBasedPractice @cmh.edu

Link to synopsis and references

Last Updated: 7.03.2024

End of Life: Nutrition, Hydration, & GI Symptom Management

Associated Power Plans: End of Life Pathway, End of Life PCA

Children's Mercy KANSAS CITY | Evidence Based Practice

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

Is patient interested in eating/drinking?

No → Is lack of interest in eating/drinking related to other symptoms?

No → *Loss of appetite and thirst are normal and expected*

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

Yes → **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.

Yes → 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

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
Non-pharmacologic	***Medications***	***Medications***
• Relaxation • Biofeedback • Acupuncture • Aromatherapy	• Ondansetron: 0.15 mg/kg/dose PO/IV q8h PRN (max 8 mg per dose) • Promethazine: >2 yo: 0.25 mg/kg/dose PO/IV q 6-8h PRN (max 1 mg/kg/24h) • Scopolamine (Transdermal) q72h: 1 mo - 2 yo: 1/4 patch 3 yo - 9 yo: 1/2 patch 10 yo - 17 yo: 1 patch • Metoclopramide: 0.01-0.02 mg/kg/dose IV q4h • Haloperidol: • 0.01 - 0.02 mg/kg/dose PO q30 minutes PRN	• Lactulose • Polyethylene glycol • Docusate/senna • Methylnaltrexone

Contact: EvidenceBasedPractice @cmh.edu

Link to synopsis and references

Last Updated: 7.03.2024