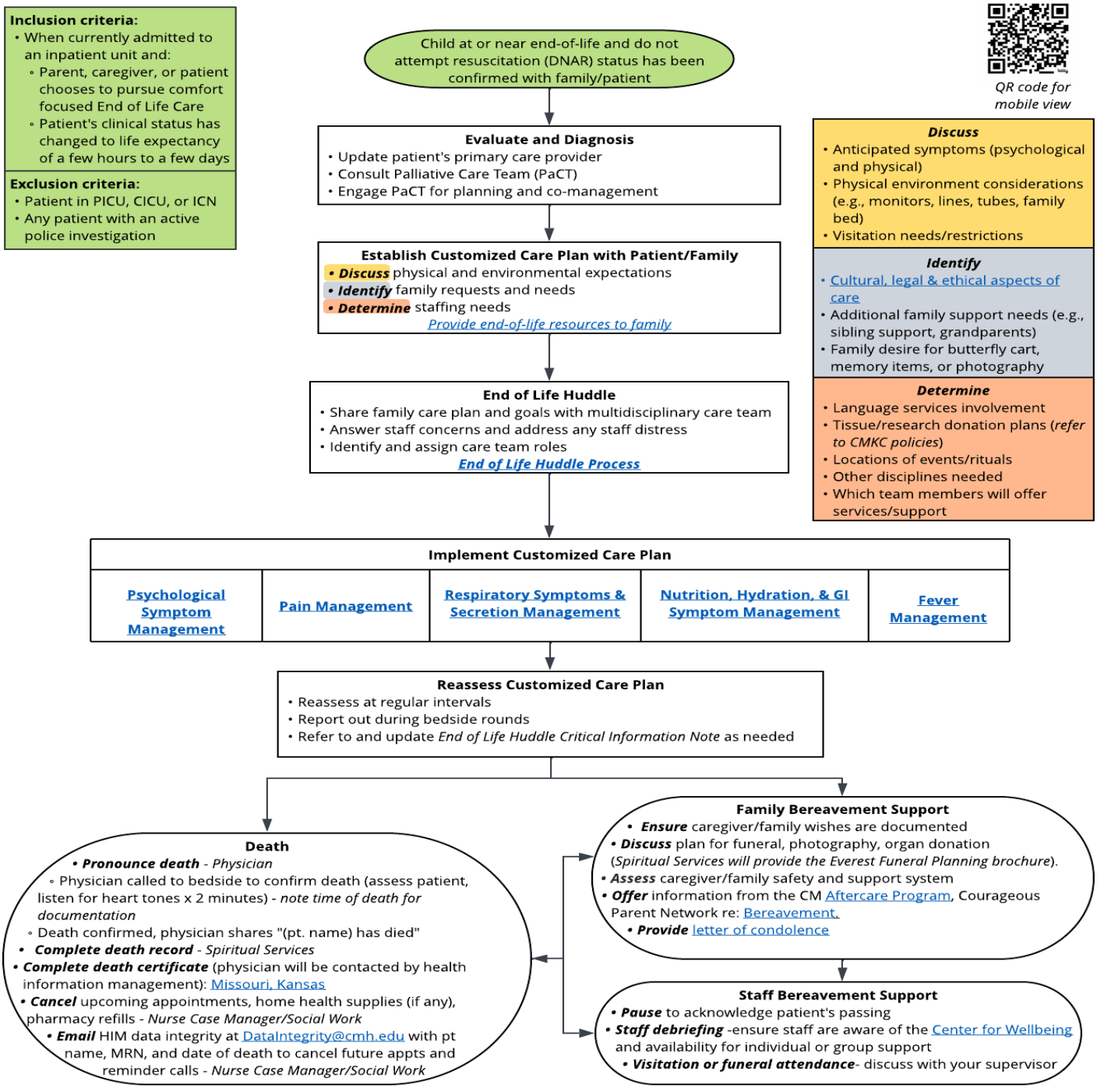
End of Life
Clinical Pathway Synopsis

End of Life: Continuum Algorithm



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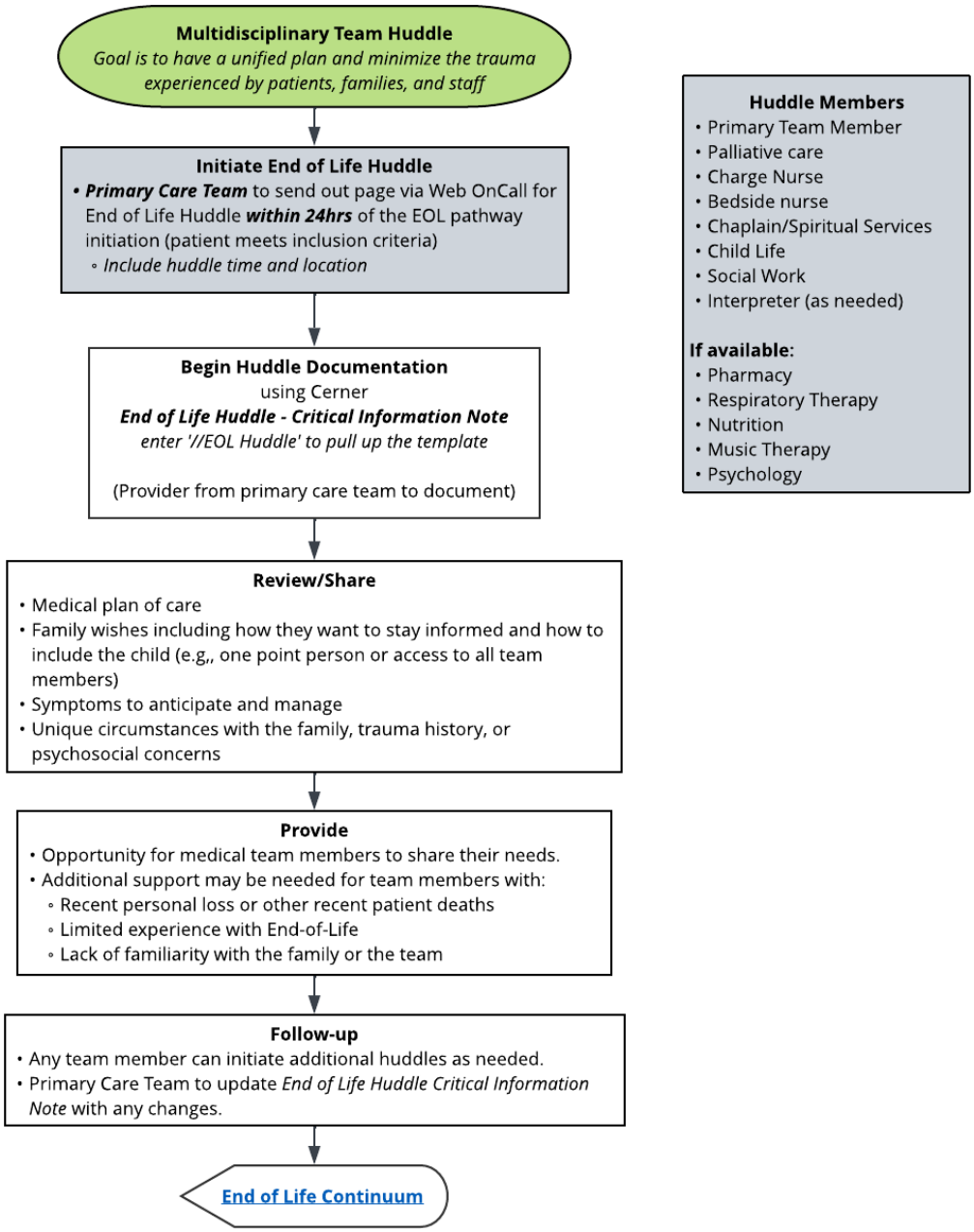
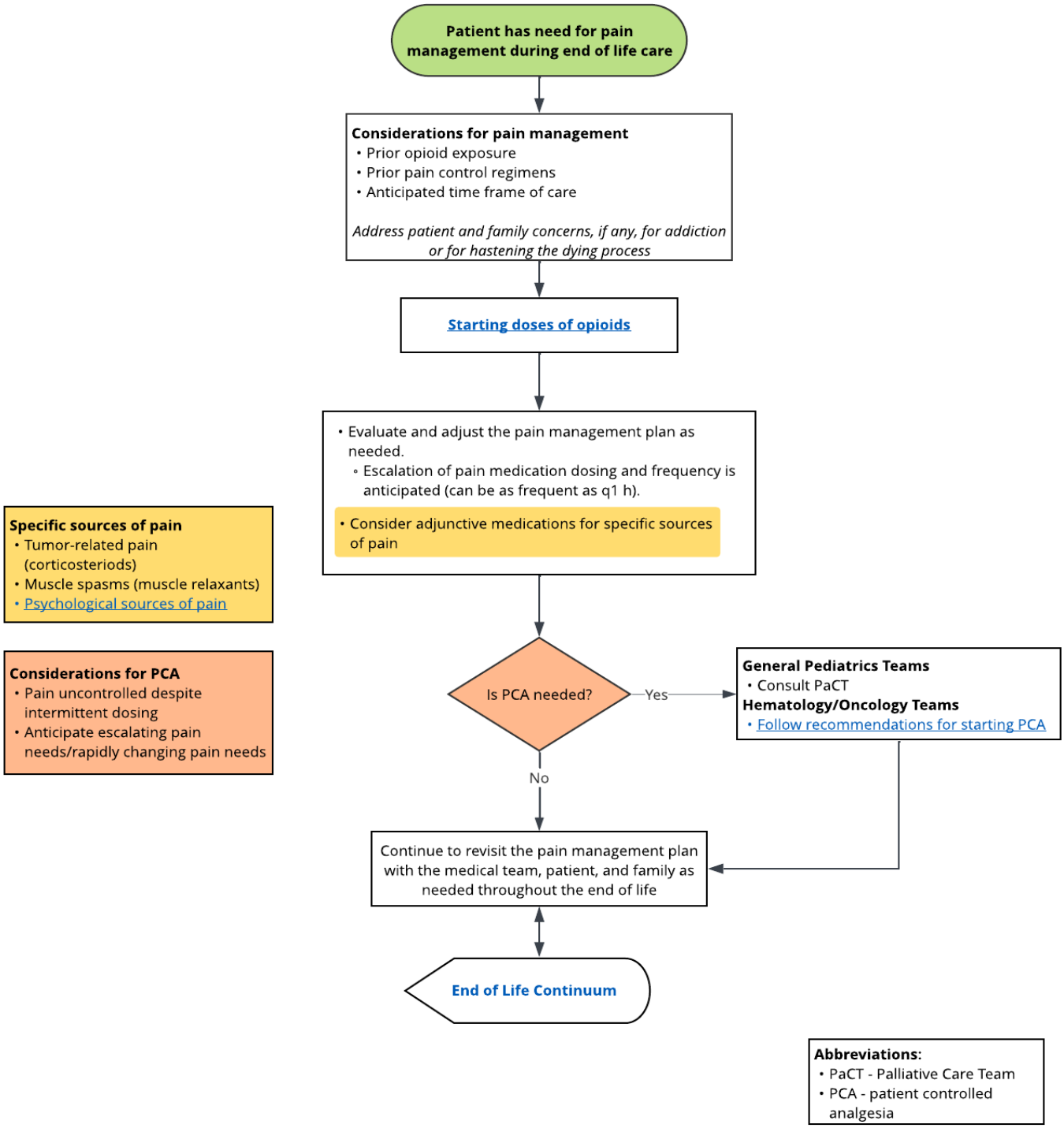
End-of-Life: Huddle Process Algorithm



End of Life: Pain Management Algorithm



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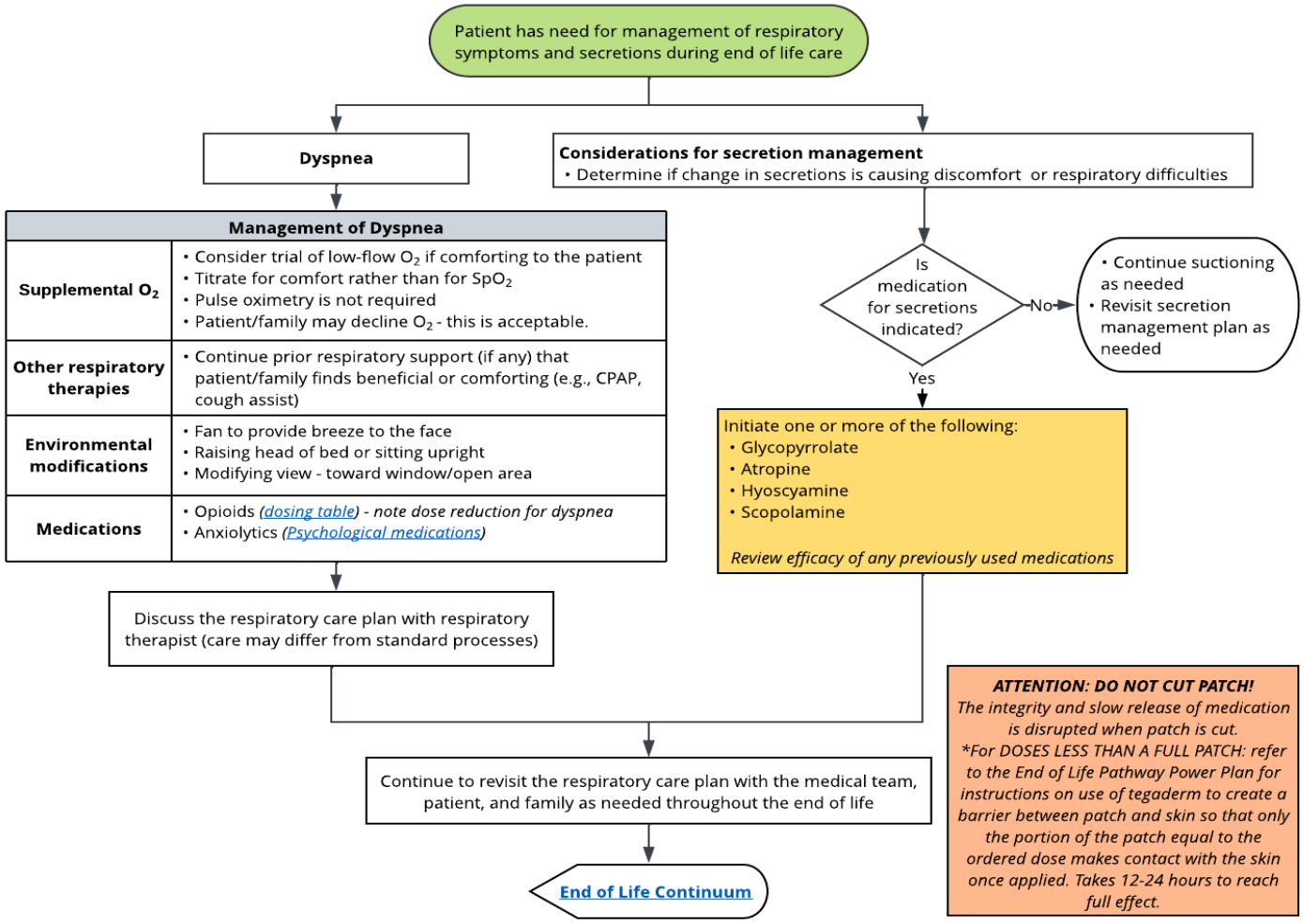
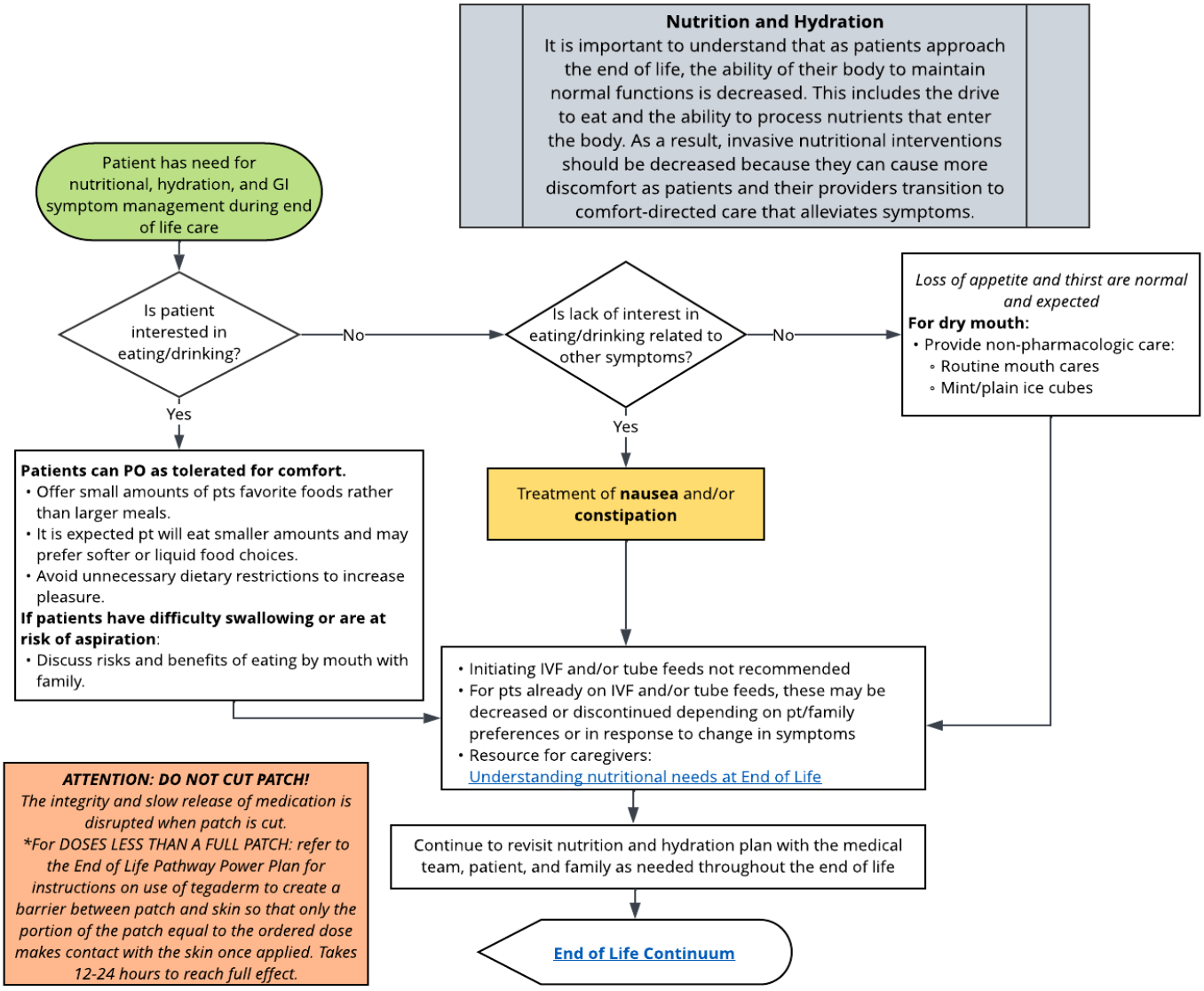
End of Life: Respiratory Symptoms & Secretion Management Algorithm



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

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



Nausea		Constipation
Non-pharmacologic • Relaxation • Biofeedback • Acupuncture • Aromatherapy	***Medications*** • 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	***Medications*** • Lactulose: 7.5 ml PO, BID 15 ml PO, BID • Polyethylene glycol: 8.5 gm PO, BID 17 gm PO, BID • Docu-sate/senna: 1 tablet PO, BID 2 tablets PO, BID • Methylnaltrexone: 0.15 mg/kg (max dose 12 mg)

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Objective of Clinical Pathway

To provide care standards for the child at or near end of life and transitioning to comfort care within the hospital, outside of an ICU environment. The End-of-Life Clinical Pathway is intended to provide guidance for assessment, symptom management, communications for the care team (including families) and bereavement support to minimize care variation.

Background

End-of-life care can be stressful and uncertain for all caregivers, both family and medical staff, but it becomes exponentially overwhelming for those caring for children. The child mortality rate in the United States is around 37,000 children before the age of 18 years (National Center for Fatality Review and Prevention, 2024). When life-sustaining care transitions to comfort care, there becomes an increased need to reduce the emotional burden and discomfort during the end of life by establishing guided palliative care processes. These include providing the family with patient-focused support resources, ensuring patient comfort, respecting patient and family values and wishes, and optimizing the time families have with their child.

In addition to the burden of emotional stress, families experience barriers to accessing in-home end-of-life care for their child. Based on the 2020 National Hospice and Palliative Care Organization's Pediatric Needs Assessment, 71.5% of counties in the United States do not offer home-based hospice care (Fisher et al., 2023). Patients with serious illness and their family caregivers are seldom able to have their care needs reliably met, leading to symptom exacerbation crises, emergency department visits, and/or repeated hospitalizations (Fishman et al., 2009). Beyond geographical barriers to access, there are also racial and ethnic disparities in access to specialty centers and in-home hospice for end-of-life care (Johnston et al., 2019; Kaye et al., 2019). Due to the lack of options for in-home end-of-life care, many families have turned to or been directed to the hospital setting for their child's end-of-life care. Thus, establishing guided practice standards for inpatient end-of-life care is of utmost importance.

The American Academy of Pediatrics (AAP, 2022) and the National Coalition for Hospice and Palliative Care (NCHPC, 2018) have established guidance for healthcare workers providing end-of-life care. The guidance emphasizes the importance of good communication among healthcare workers and between healthcare workers and families, providing clarity on end-of-life care options and management. Palliative care through an interdisciplinary team should offer psychological, physical, spiritual, and emotional support to enhance the quality of life of the patient, their family, and caregivers (NCHPC, 2018). National and local guidelines fostered the interprofessional, transparent, culturally informed, and equitable care approach adopted by our Children's Mercy inpatient medical team when developing our guided palliative care process, the End-of-Life Continuum Clinical Pathway.

Target Users

- Physicians (Palliative Care, Acute Pain Service, Hematology/Oncology, Hospital Medicine, Fellows, Residents)
- Advanced Practice Nurses
- Nurses (Charge and bedside nurses)
- Chaplains
- Child Life Specialists
- Respiratory Therapists
- Social Workers
- Music Therapists
- Nutritionists
- Psychologists

Target Population

Inclusion Criteria

- Patient currently admitted to an inpatient unit and:
  - Parent, caregiver, or patient chooses to pursue comfort-focused end-of-life care
  - Patient 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

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AGREE II

The American Academy of Pediatrics (Linebarger et al., 2022) and the National Consensus Project for Quality Palliative Care (2018) national guideline(s) guided the End-of-Life Clinical Pathway Committee. See Tables 1 and 2 for AGREE II.

Table 1

AGREE II[a] Summary for the American Academy of Pediatrics Guideline on Pediatric End of Life Care, (Linebarger et. al. 2022).

Domain	Percent Agreement	Percent Justification^
Scope and purpose	100%	The guideline's aim, the clinical questions posed, and the target populations **were** identified.
Stakeholder involvement	76%	The appropriate stakeholders developed the guideline and represented the views of its intended users.
Rigor of development	37%	The guideline developers **did not** provide how the evidence was gathered and synthesized, how the recommendations were formulated nor how the guidelines will be updated.
Clarity and presentation	90%	The guideline recommendations **are** clear, unambiguous, and easily identified; different management options are also presented.
Applicability	60%	Barriers and facilitators to implementation **were addressed**. However, strategies to improve utilization and resource implications **were not included** in the guideline.
Editorial independence	73%	The recommendations **were not** biased with competing interests.
Overall guideline assessment	73%	
See Practice Recommendations		

Note: Three EBP Scholars completed the AGREE II on this guideline.
^Percentage justification is an interpretation based on the Children's Mercy EBP Department standards.

Table 2

AGREE II[a] Summary for the Clinical Practice Guidelines for Quality Palliative Care (National Consensus Project for Quality Palliative Care, 2018).

Domain	Percent Agreement	Percent Justification^
Scope and purpose	100%	The aim of the guideline, the clinical questions posed, and target populations **were** identified.
Stakeholder involvement	95%	The guideline **was developed** by the appropriate stakeholders and represents the views of its intended users.
Rigor of development	85%	The process used to gather and synthesize the evidence, the methods to formulate the recommendations and to update the guidelines **were** explicitly stated.
Clarity and presentation	95%	The guideline recommendations **are** clear, unambiguous, and easily identified; in addition, different management options are presented.
Applicability	94%	Barriers and facilitators to implementation, strategies to improve utilization, and resource implications **were addressed** in the guideline.
Editorial independence	93%	Competing interests did not bias the recommendations.
Overall guideline assessment	94%	
See Practice Recommendations		

Note: Three EBP Scholars completed the AGREE II on this guideline.
^Percentage justification is an interpretation based on the Children's Mercy EBP Department standards.

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Practice Recommendations

Please refer to the American Academy of Pediatrics (Linebarger et al., 2022) and the National Consensus Project for Quality Palliative Care (2018) national guideline(s) for full practice recommendations, evaluation, and treatment recommendations.

Additional Questions Posed by the Clinical Pathway Committee

No additional clinical questions beyond those addressed in the above guidelines were posed for formal literature review.

Recommendation Specific for Children's Mercy

No deviations were made from the American Academy of Pediatrics (Linebarger et al., 2022) and the National Consensus Project for Quality Palliative Care (2018) national guideline(s) regarding practice recommendations, but logistical processes specific to Children's Mercy were added. These include:

- Providing a specific documentation template for the end-of-life huddle to improve communication. This will be referred to as the 'End-of-Life Huddle Critical Information Note.'
- Building an order set specific to comfort care for end-of-life transition.

Measures

- Utilization of the End-of-Life Clinical Pathway
- Utilization of electronic documentation for end-of-life huddle

Value Implications

- Decreased risk of overdiagnosis and/or overtreatment (i.e., continuing life-sustaining interventions when caregivers and/or patient has requested comfort care).
- Decreased unwarranted variation in care
- Increased patient and family-centeredness, focusing on patient and family values, culture, and personal preferences throughout the end-of-life
- Increased support for medical team members caring for patients at the end of life

Organizational Barriers and Facilitators

Potential Barriers

- The need for highly customized care based on patient and family values, culture, and personal preferences
- Challenges with appropriate bereavement support for caregivers and staff

Potential Facilitators

- Collaborative engagement across care continuum settings during clinical pathway development
- Standardized, multidisciplinary huddle process to improve communication of the specific plan
- Standardized order set for general and Oncology units

Diversity/Equity/Inclusion

Our aim is to provide equitable care. These issues were discussed with the Committee, reviewed in the literature, and discussed prior to making any practice recommendations.

Power Plans

- End of Life Pathway

Associated Children's Mercy Policies

The policies with asterisks are updated to align with the End-of-Life Clinical Pathway recommendations and the AAP Pediatric End-of-Life Care (2022) guideline.

- Disagreement Resolution Surrounding Redirection of Care
- Moral and Religious Objections to Care
- Care of the Patient at End of Life*

- Organ and Tissue Donation
- Organ Donation after Circulatory Death
- Authorization for Autopsy
- Post-Mortem Examination Consent
- Death Certificate Completion
- Record of Body Release
- Patient Expiration Communication Procedure
- Grief Support Policy
- Palliative Care/Terminal Care*
- Direct Release and Transport of Deceased Patient by Non-Funeral Home Entity Policy

Education Materials

- Cultural, Legal, & Ethical Aspects of Care include links to the following AAP Policy Statements:
  - Forgoing Life-Sustaining Medical Treatment
  - Forgoing Medically Provided Nutrition and Hydration in Children
    - Intended for all healthcare staff providing care for a child at end of life
- End-of-Life Resources and Support includes the following links to the Courageous Parent Network:
  - When a child dies booklet
  - End of life for your child: Preparing, Part 1
  - End of life for your child: What to expect, Part 2
  - Understanding nutritional needs
    - Intended to be informative and reassuring information for caregivers/parents
    - Available in English and Spanish
- Family Bereavement Support includes the following links:
  - Bereavement (available in English and Spanish)
  - Letter of condolence
  - Everest funeral planning assistance brochure (provided by Spiritual Services)
    - Intended for all caregivers/parents
    - Letter of condolence provides guidance for healthcare staff to write a letter to families

Clinical Pathway Preparation

This pathway was prepared by the Evidence Based Practice (EBP) Department in collaboration with the End-of-Life Clinical Pathway Committee, which is composed of content experts at Children's Mercy Kansas City. If a conflict of interest is identified, the conflict will be disclosed next to the committee member's name.

End-of-Life Clinical Pathway Committee Members and Representation

- John Stroh, MD, FAAP | Palliative Care | Committee Co-Chair
- Amy Johnson, MD, MBA | Hematology/Oncology/BMT Fellow| Committee Co-Chair
- Jenni Linebarger, MD, MPH, FAAP, FAAHPM | Palliative Care | Committee Member
- Julia Hays, MD | Hematology/Oncology/BMT | Committee Member
- Chris Klockau, RPh, BCOP | Pharmacy | Committee Member
- Ashley Daly, MD | Hospital Medicine | Committee Member
- Becky Crouse, DMin, MDiv, BCC | Spiritual Services | Committee Member
- Corey Pagnotta, DO | Resident | Committee Member
- Aly Schmidt, MSN, RN, CPN, CHPPN | Palliative Care | Committee Member

Family Committee Member

- Jana Rajas, MPT | Patient Family Engagement |Committee Member

EBP Committee Members

- Kathleen Berg, MD, FAAP | Evidence Based Practice
- Andrea Melanson, OTD, OTR/L | Evidence Based Practice

Clinical Pathway Development Funding

The development of this clinical pathway was underwritten by the following departments/divisions: Palliative Care, Hematology/Oncology, Hospital Medicine, Pharmacy, Spiritual Services, and Evidence Based Practice.

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Conflict of Interest

The contributors to the End-of-Life Clinical Pathway have no conflicts of interest to disclose related to the subject matter or materials discussed.

Approval Process

- This pathway was reviewed and approved by the End-of-Life Clinical Pathway Committee, Content Expert Departments/Divisions, and the EBP Department, after which they were approved by the Medical Executive Committee.
- Pathways are reviewed and updated as necessary every 3 years within the EBP Department at CMKC. Content expert teams are involved with every review and update.

Review Requested

Department/Unit	Date Approved
Palliative Care	June 14, 2024
Hematology/Oncology	June 5, 2024
Pharmacy	June 14, 2024
Hospital Medicine	June 19, 2024
Spiritual Services	June 7, 2024
Patient Family Engagement	May 28, 2024
Evidence Based Practice	June 19, 2024

Version History

Date	Comments
July 2024	Version one – Developed clinical pathway, power plans, and clinical documentation template
October 2024	Version two – added medication dosing to constipation medications

Date for Next Review

- July 2027

Implementation & Follow-Up

- Once approved, the pathway was presented to appropriate care teams and implemented. Care measurements will be assessed and shared with appropriate care teams to determine if changes need to occur.
- Order sets/power plans consistent with recommendations were created for the inpatient setting
- Education was provided to all stakeholders:
  - Nursing units where the End-of-Life Clinical Pathway is used
  - Department of Spiritual Services
  - Providers from Palliative Care, Hematology/Oncology, and Hospital Medicine
- Additional institution-wide announcements were made via email, the hospital website, and relevant huddles.

Disclaimer

When evidence is lacking or inconclusive, options in care are provided in the supporting documents and the power plan(s) that accompany the clinical pathway.

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References

Ferrell, B. R., Twaddle, M. L., Melnick, A., & Meier, D. E. (2018). National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines, 4th Edition. *J Palliat Med*, *21*(12), 1684–1689. https://doi.org/10.1089/jpm.2018.0431

Fisher, D., Hawley, B., James, K., Lindley, L.C., Samson, K., Smith, S.M., Torkildson, C., & Weaver, M.S. (2023). Pediatric facts and figures. *National Hospice and Palliative Care Organization*. https://www.nhpco.org/wp-content/uploads/NHPCO_Pediatric_Facts_Figures_2023.pdf

Fishman, J., O'Dwyer, P., Lu, H.L., Henderson, H., Asch, D.A., & Casarett, D.J. (2009). Race, treatment preferences, and hospice enrollment: Eligibility criteria may exclude patients with the greatest care needs. *Cancer, 115*(3), 689–697.

Johnston, E. E., Bogetz, J., Saynina, O., Chamberlain, L.J., Bhatia, S., & Sanders, L. (2019). Disparities in inpatient intensity of end-of-life care for complex chronic conditions. *Pediatrics, 143*(5), e20182228

Kaye, E., Gushue, C., DeMarsh, S., Snaman, J., Blazin, L., Johnson, L., Levine, D., & Baker, J. (2019). Impact of race and ethnicity on end-of-life experiences for children with cancer. *The American Journal of Hospice & Palliative Care, 36*(9), 767–774. https://doi.org/10.1177/1049909119836939

Linebarger, J. S., Johnson, V., Boss, R. D., Collura, C. A., Humphrey, L. M., Miller, E. G., Williams, C. S. P., Rholl, E., Ajayi, T., Lord, B., & McCarty, C. L. (2022). Guidance for Pediatric End-of-Life Care. *Pediatrics*, *149*(5). https://doi.org/10.1542/peds.2022-057011

National Center for Fatality Review and Prevention. (2024, March). *Child death review*. The National Center for Child Death Review. https://ncfrp.org/cdr/