

End of Life Care Pathway v2.1: Table of Contents

Stop and Review

Inclusion Criteria

- Decision to withdraw or limit life sustaining therapies and/or anticipated death during this hospitalization or at home
- OR
- Patient has died

End of Life Care

Pre-Death

Medication

Organ Donation

Post-Death Care Part 1

Post-Death Care Part 2

Tissue Donation

Post-Family Discharge

Staff Support

Decedent Transport

Start on this page if the patient was put on pathway post-death.
If patient has been on pathway Pre-Death, go to Post-Death Part 2.

Viewing Patients Outside of the Morgue

Staff Support Questions

External Contact Information

Appendix

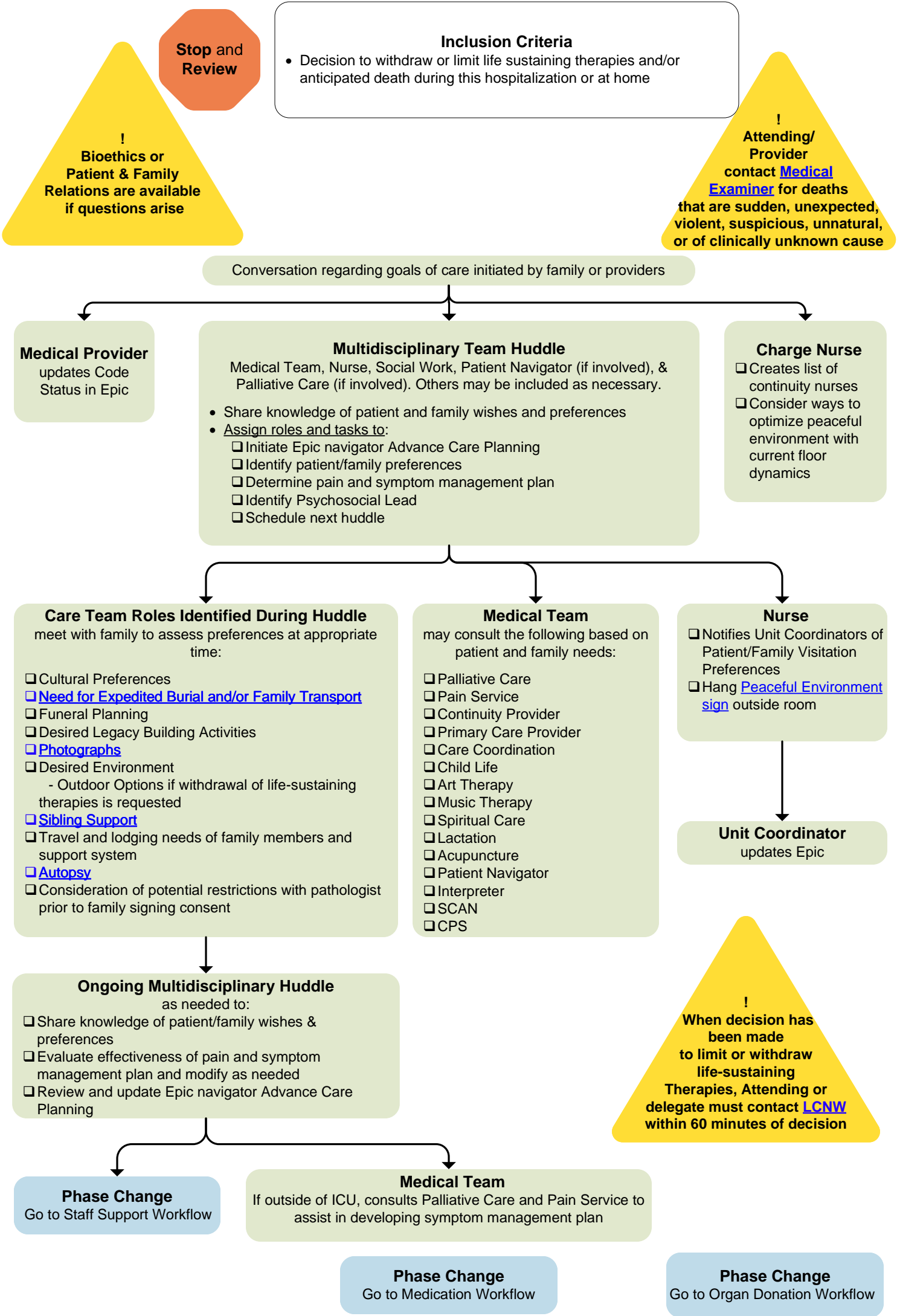
Version Changes

Approval & Citation

Evidence Ratings

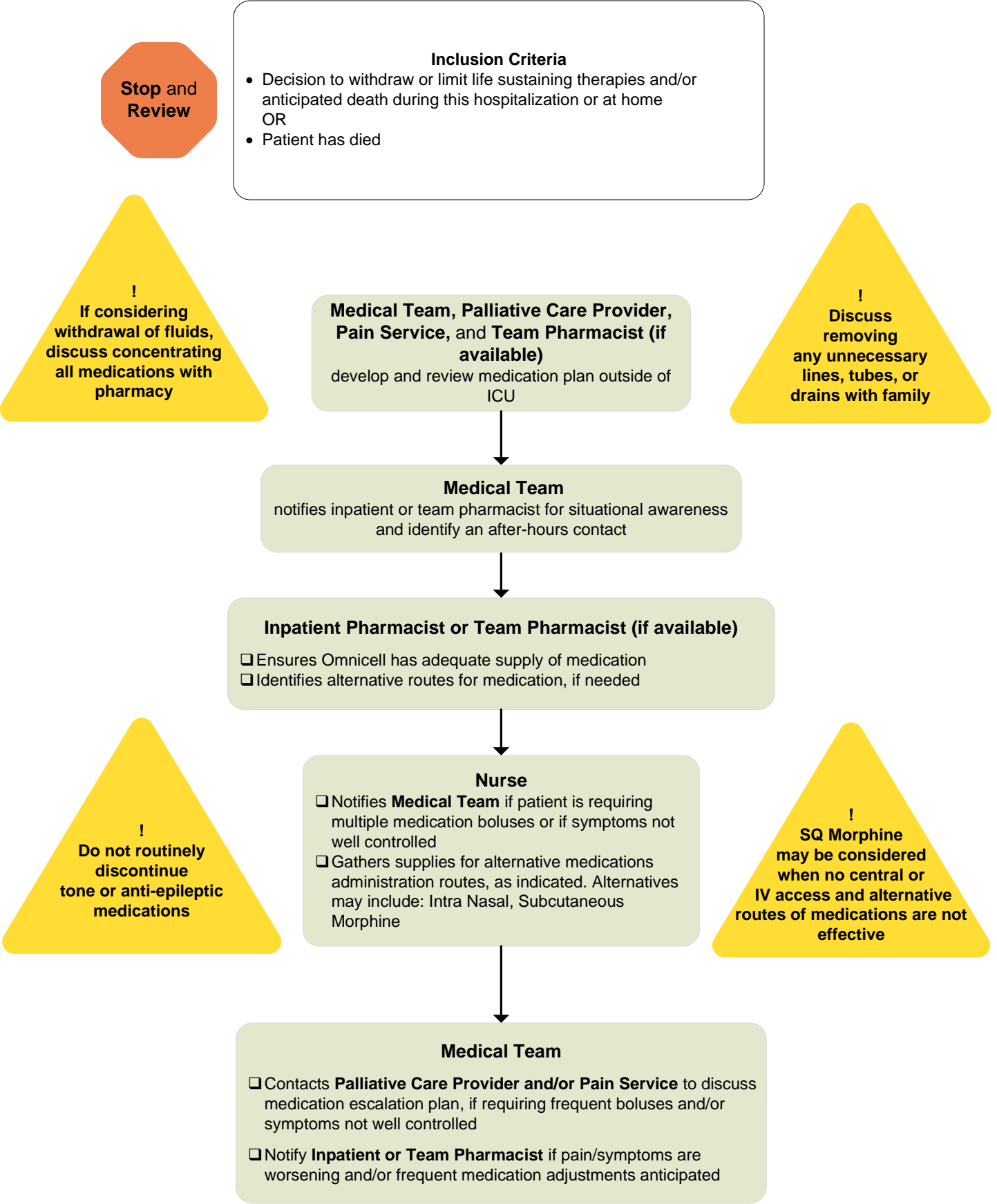
Bibliography

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End of Life Care Pathway v2.1: Organ Donation

Stop and Review

Inclusion Criteria

- Decision to withdraw or limit life sustaining therapies and/or anticipated death during this hospitalization or at home
OR
- Patient has died

Attending or delegate

- ❑ Contact Life Center Northwest ([LCNW](#)) Statline within **60 minutes** after the decision to withdraw or limit life sustaining therapies has been made. Discuss illness/injury, care plan, past medical history, and family dynamics
Also contact LCNW if:
 - Imminent death outside of withdraw or limiting life sustaining therapies and/or
 - Substantial brain injury and/or
 - Family requests organ donation
- ❑ Record date, time, and contact person on Epic navigator Discharge as Deceased

LCNW

arrives onsite within **24 hours** to evaluate for donation suitability if not excluded by phone

If family has questions regarding the process or would like additional information, consider contacting [LCNW](#) to determine if they are available to speak with the family

Is patient medically suitable candidate for Organ Donation?

!
Medical Examiner (ME) cases are still eligible for donation.
[LCNW](#) will coordinate with ME for ME cases.

NO YES

Attending or delegate

- ❑ Contacts LCNW Statline within **60 minutes** after death to evaluate for tissue donation suitability
- ❑ Records date, time, and contact person on Epic navigator Discharge as Deceased

LCNW or affiliate

will contact family by phone within 24 hours if patient is eligible for tissue donation

Attending, Nurse, Charge Nurse, Social Work
huddle with LCNW to make plan for collaborative donation conversation

LCNW representative and Medical Team (if appropriate)

meet with family to discuss organ donation. May also discuss tissue and cornea donation at that time

Does family consent to donation?

YES

If family wishes to proceed with organ donation reference Seattle Children's Policy and Procedures

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End of Life Care Pathway v2.1: Post-Death Part 1

Start on this page if the patient was put on pathway after their death.
If patient has been on pathway prior to death, go to [Post-Death Part 2](#).

Stop and Review

Inclusion Criteria

- Decision to withdraw or limit life sustaining therapies and/or anticipated death during this hospitalization or at home
- OR
- Patient has died

!
Attending/Provider contact [Medical Examiner](#) for deaths that are sudden, unexpected, violent, suspicious, unnatural, or of clinically unknown cause

Multidisciplinary Team Huddle

Medical Team, Nurse, Social Work, Patient Navigator (if involved), and Palliative Care (if involved). Others may be included, as necessary:

- Share existing knowledge of patient and family wishes and preferences
- Assign task and roles to:
 - ☐ Initiate Epic navigator Advance Care Planning
 - ☐ Determine patient and family preferences and cultural needs
 - ☐ Determine when next huddle will be.
 - ☐ Identify psychosocial lead to follow up with family support plan

Care Team Roles Identified During Huddle

meet with family to assess preferences at appropriate time:

- ☐ Cultural Preferences
- ☐ [Need for Expedited Burial and/or Family Transport](#)
- ☐ Funeral Planning
- ☐ Desired Legacy Building Activities
- ☐ [Photographs](#)
- ☐ Desired Environment
- ☐ [Sibling Support](#)
- ☐ Travel and lodging needs of family members and support system
- ☐ [Autopsy](#) - consideration of potential restrictions with pathologist prior to family signing consent

Lactation After Loss

- Job Aid: Milk Management for Nursing: Infant Demise, 14221 (*for SCH only*)
- Consent of Release of Breastmilk for Donation (*for SCH only*)

Medical Team

consults the following based on patient and family needs:

- ☐ Child Life
- ☐ Care Coordination
- ☐ Spiritual Care
- ☐ Lactation
- ☐ Music Therapy
- ☐ Patient Navigator
- ☐ Interpreter
- ☐ SCAN
- ☐ CPS

Ongoing Multidisciplinary Huddle

as needed to:

- ☐ Share knowledge of patient/family wishes & preferences
- ☐ Review Epic navigator Advance Care Planning to ensure completion of tasks

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End of Life Care Pathway v2.1: Post-Death Part 2

Stop and Review

Inclusion Criteria

- Decision to withdraw or limit life sustaining therapies and/or anticipated death during this hospitalization or at home
OR
- Patient has died

Attending (or delegate)

- ☐ Reference Provider Job Aid for additional information
- ☐ Initiate Epic navigator Advance Care Planning, if not already done
- ☐ Complete electronic death record in [EDRS](#) (only need date, time and signature for ME cases or if autopsy is being performed)
- ☐ Autopsy Permission/Refusal Form (44353)
- ☐ Give completed forms to Unit Coordinator
- ☐ Notify PCP and Continuity Providers
- ☐ If inpatient, complete Epic navigator Discharge as Deceased
- ☐ Contact LCNW within 60 minutes after patient's death

Charge Nurse

- ☐ Notify Shift Administrator of patient death
- ☐ Consider ways to optimize peaceful environment with current floor dynamics

Psychosocial Lead

Ensure family follow-up preferences are documented in the Epic navigator Advance Care Planning

Nurse

- ☐ Notify Unit Coordinator with Time of Death
- ☐ Determine if family would like to participate in post-mortem care

Unit Coordinator

- ☐ Updates Epic to not contact family
- ☐ Prepare documents for transport with patient's body

Nurse Case Manager and Care Coordinator

- ☐ Cancel upcoming appointments
- ☐ Notify home nursing agencies of patient's death
- ☐ Coordinate with home care companies to cancel supply shipments and arrange pick up of durable medical equipment
- ☐ Notify outside pharmacy to cancel refill medications

!
Attending or delegate must contact [LCNW](#) within 60 minutes after patient's death

Phase Change
Go to Tissue Donation

- Allow Family/Caregivers time with patient and perform care and rituals, as needed
- Key members of the team continually re-assess family needs and update Epic navigator Advance Care Planning

Social Work

(Prior to Discharge)

- ☐ Assess family safety & immediate support system
- ☐ Complete Journey Navigator
- ☐ Provide family with grief literature, as appropriate, from Unit-Based Journey box

!
If concerns for family safety, escalate to medical team and social work

Nurse

- ☐ Perform post-mortem cares with family if desired. Discuss with medical team prior to removing any lines, tubes, or drains
- ☐ Obtain shroud from Central Services
- ☐ Notifies **Charge Nurse** when patient is ready to be transported to the morgue

Shift Administrator

- ☐ Notify **Security** to bring cart, if needed, and to unlock the morgue

Nurse, Shift Administrator, and/or Security

- ☐ Transport patient to the morgue
 - Family may accompany staff and patient, if strongly desires. Coordinate with Pathology, Psychosocial Lead, and Medical Team to ensure adequate family support is in place prior to transport
 - Independent transport by staff to and from the morgue is not recommended

When family is ready to leave, escort family to exit

Phase Change
Go to Post-Family Discharge

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End of Life Care Pathway v2.1: Tissue Donation

Stop and Review

Inclusion Criteria

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OR
- Patient has died

Attending or delegate

- ☐ Contacts LCNW Statline within **60 minutes** after death to evaluate for tissue donation suitability
- ☐ Records date, time, and contact person in the Epic navigator Discharge as Deceased

LCNW or affiliate

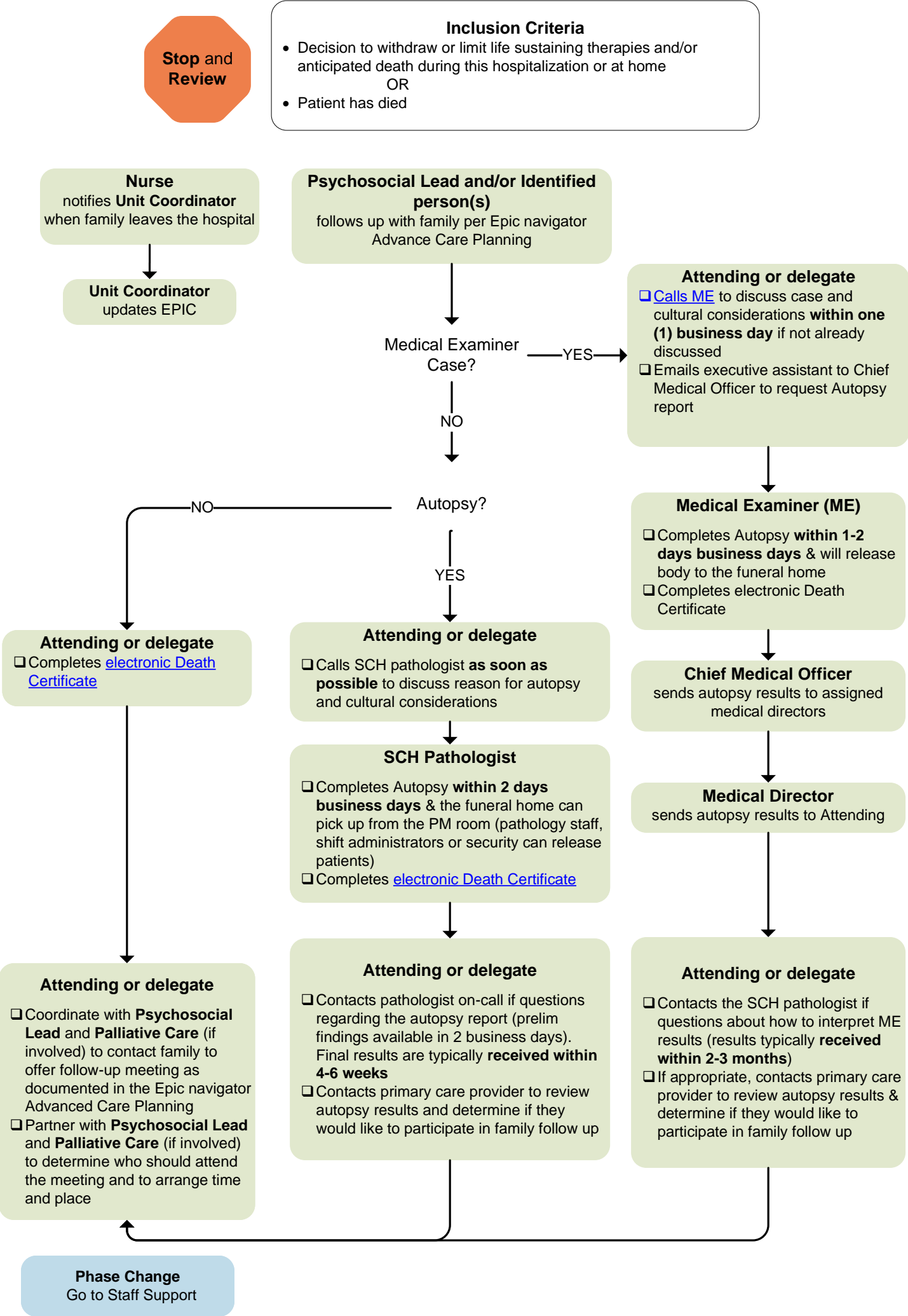
will contact family by phone within 24 hours if patient is eligible for tissue donation

If family has questions regarding the process or would like additional information, consider contacting [LCNW](#) to determine if they are available to speak with the family

!
Medical Examiner (ME) cases are still eligible for donation.
[LCNW](#) will coordinate with ME for ME cases

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End of Life Care Pathway v2.1: Post-Family Discharge



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End of Life Care Pathway v2.1: Staff Support

Stop and Review

Inclusion Criteria

- Decision to withdraw or limit life sustaining therapies and/or anticipated death during this hospitalization or at home
- OR
- Patient has died

Nurse

notifies Charge Nurse of anticipated death or limitations in cares

Staff Support Pre-Death

Senior Resident or Attending
notify Chief Residents of anticipated death or change in goals of care

Charge Nurse & Area Leader

huddle to consider:

- ☐ Staff support
- ☐ Unit support
- ☐ Anticipated off-policy request
- ☐ Individual RN support
- ☐ Family needs

Nursing Leader

escalates support needs for additional team members:

- ☐ Medical Providers
- ☐ Respiratory Therapy
- ☐ Environmental Services
- ☐ Child Life
- ☐ Social Work
- ☐ Medical Providers
- ☐ Nutrition Team
- ☐ Additional team members, as appropriate

Chief Residents

- ☐ Consider Resident team support
- ☐ Consider individual Resident support
- ☐ Communicate any alteration in admissions planning to Shift Administrator

Nurse & Charge Nurse

Ongoing huddles as needed to [assess staff needs](#)

Residents & Chief Residents

Ongoing huddles as needed to [assess staff needs](#)

Staff Support Post-Death

Nurse and Charge Nurse

huddle as soon as possible

☐ [Assess nurse's needs](#):

- Informational
- Emotional
- Practical (anticipated barriers)
- Spiritual
- ☐ Assess nurse staffing to determine if Nurse can take a break or choose to leave early.

Senior Resident or Attending

huddles with resident team as soon as possible

Charge Nurse

- ☐ Notifies Area Leader during the day. If death occurs during the night or on weekends, escalate to the Leader on call, at his/her discretion
- ☐ Contacts Staff Support Team if needed emergently. Outside regular business hours, page on-call Spiritual Care chaplain who covers Staff Support
- ☐ Communicates with unit leadership team. Include the patient's name, date/time of death, and staff involved in caring for the child

Senior Resident

notifies Chief Residents of patient's death. Include date, time, and staff names in communication

Staff Support Post-Family Discharge

Nurse Manager

- ☐ Follow-up with staff involved within one business day
- ☐ Acknowledge loss
- ☐ [Assess staff needs](#)
- ☐ Share available resources
- ☐ Notify Staff Support Team of patient death on next business day for situational awareness and to relay any additional support requests

Chief Resident

checks in with primary resident within one business day of patient's death to assess coping and notify him/her of available support services

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End of Life Care Pathway v2.1: Decedent Transport

Stop and Review

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OR
- Patient has died

Business hours for [King County Dept Vital Statistics](#) is M-F, 8:30a – 4:30p

Social Work or Psychosocial Lead

- ☐ Identify funeral home or cemetery that will be receiving patient for immediate burial
- ☐ Notify Pathology with burial plan

Pathology Dept

will take care of preparing and signing the Death Certificate and arrange transport of the Decedent with the family

Autopsy?

←NO→

→YES→

Phase Change

Go to Post-Family Discharge

Can family or agent travel to Dept. of Vital Statistics before end of business hours?

NO

YES

Attending

completes Electronic Death Certificate

Attending

- ☐ Complete paper Washington State Certificate of Death attached to Family Transport of a Decedent Job Aid (electronic DC does not need to be completed)
- ☐ Place copy in paper chart and give the original form with Washington State Burial Transit Permit to the family

Family or their agent

must physically take the signed Death Certificate and pay fee to the to the Dept of Vital Statistics

Deputy Registrar

approves, stamps, and signs BTP

Attending or delegate

- ☐ Copies BTP, places copy in SCH paper chart, and gives the original to the family
- ☐ Escorts family and body to the exit when family is ready to leave

Funeral Home

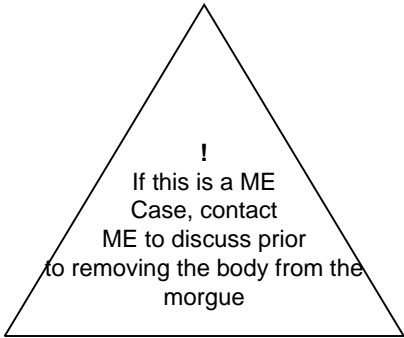
faxes Burial Transport Permit (BTP) to SCH per the Care at Death, Organ Donation, and Autopsy Policy (10189) (*for SCH only*)

Phase Change

Go to Post-Family Discharge

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End of Life Care Pathway v2.1: Viewing Patients Outside of the Morgue



Nurse or Social Work

- ☐ Determine date and time family would like to view the patient's body
- ☐ Determine if the family would like to perform any cultural rituals or legacy building activities

Operational Charge Nurse, Nurse, and Social Work develop and review plan

Operational Charge Nurse (or delegate)

- ☐ Assign Staffing
- ☐ Assign Room*
- ☐ Notify Security Unit Coordinator, Shift Administrator, and Pathology (business hours only) of plan

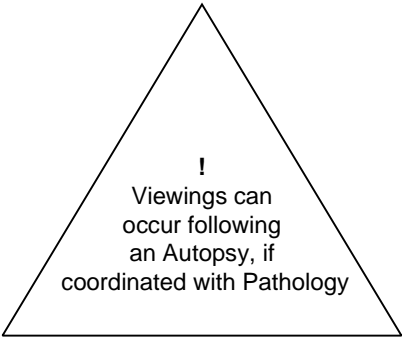
Nurse (or delegate), Security, and Pathology (business hours only) transport patient from morgue to unit

Nurse prepares patient's body** and room

Family arrives. Consider having designated person meet at the hospital entrance and escort to the room.

*Availability of unit based staffing and room assignments may vary based on patient census and environmental factors. If the unit on which the patient died is unable to accommodate this request please contact the NICU, PICU, or CICU operational charge to see if they may be able to accommodate this request. May consider the use of the NICU conference room, PICU/CICU quiet rooms if appropriate. Coordinate with Pathology to use the morgue if no unit is able to accommodate this request.

** Pathology can assist with preparing body during regular business hours; contact Pathology Admin for assistance. May wrap body in warm blankets prior to family arrival. Attempt to limit exposure to room temperature to approximately 2 hours.



Family

- ☐ Visits with patient
- ☐ Performs cultural rituals or additional legacy building activities per their preference

Nurse (or delegate)

- ☐ Visits with patient
- ☐ Periodically checks on family to assist as needed with legacy building activities
- ☐ Activates Security if needed
- ☐ Notifies Operational Charge Nurse when family is ready to leave

Social Work

- ☐ Coordinates with Nurse (or delegate) to assist with family support as available

Family leaves. Consider having designated person escort family to the exit

Nurse (or delegate)

- ☐ Prepares body to return to morgue
- ☐ Notify Security that the patient is ready to return to the morgue

Operational Charge Nurse (or delegate)

- ☐ Notify Shift Administrator when patient has been returned to the morgue

Nurse (or delegate), Security, and Pathology (business hours only) transport patient from unit to the morgue

External Contact Information

Medical Examiner Office: (206) 731-3232

LifeCenter Northwest 24/7 Statline: (888) 543-3287

[Soulumination](#): (206) 297-0885

[King County Vital Statistics Office](#): (206) 897-5100 or (800) 325-6165

Harborview Medical Center
Ninth & Jefferson Building, 2nd Floor
908 Jefferson St
Seattle, WA 98104

Hours: 8:30a – 4:30p

**Return to Post-Death Care
Part 1**

**Return to Post-Death Care
Part 2**

Return to Organ Donation

Return to Pre-Death Care

**Return to Decedent
Transport**

**Return to Post-Family
Discharge**

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Staff Support: Suggested Open-Ended Questions

“I want to check in with you about the situation/death that you experienced. Every situation/death is different, and some impact us harder than others. What would be helpful for you? Would you like to take some time away from direct care (e.g. taking a walk outside, getting a meal, grabbing coffee/drink, or do you need to leave early)?”

“Sometimes it’s helpful to think about what resources are available here and when you are at home.

- In the hospital, your immediate leadership is available, you could connect with peers and colleagues, chat with someone from Staff Support, or talk with a chaplain from Spiritual Care. Would you like me to call someone for you?
- In your circle outside of the hospital, there may be friends or family, a faith community, or other resources you would find helpful.
- The Employee Assistance Program is also a resource for you.”

Resource Links:

Employee Assistance Program (*for SCH only*)

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Summary of Version Changes

- **Version 1.0 (11/5/2018):** Go live.
- **Version 1.1 (7/1/2019):** Added contacts to Internal Contact Information p2; updated Care Coordination tasks to Post-Death Part 2.
- **Version 1.2 (7/16/2020):** Added Appendix item, Viewing Patients Outside the Morgue.
- **Version 1.3 (1/5/2021):** Updated algorithm to align with changes due to migration to new electronic health record (Epic).
- **Version 2.0 (6/15/2021):** Added link and verbiage relevant to Subcutaneous Job Aid, aligned verbiage to match policies, and updated algorithm to new CSW template.
- **Version 2.1 (1/9/2024):** Updated link for staff support services, deleted CultureVision resource as it is no longer available, and added resources for lactation following loss.

Approval & Citation

Approved by the CSW End of Life Care & Bereavement team for November 5, 2018, go-live

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Retrieval Website: <https://www.seattlechildrens.org/pdf/end-of-life-care-and-bereavement-pathway.pdf>

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Evidence Ratings

This pathway was developed through local consensus based on published evidence and expert opinion as part of Clinical Standard Work at Seattle Children's. Pathway teams include representatives from Medical, Subspecialty, and/or Surgical Services, Nursing, Pharmacy, Clinical Effectiveness, and other services as appropriate.

When possible, we used the GRADE method of rating evidence quality. Evidence is first assessed as to whether it is from randomized trial or cohort studies. The rating is then adjusted in the following manner (from: Guyatt G et al. J Clin Epidemiol. 2011;4:383-94, Hultcrantz M et al. J Clin Epidemiol. 2017;87:4-13.):

Quality ratings are *downgraded* if studies:

- Have serious limitations
- Have inconsistent results
- If evidence does not directly address clinical questions
- If estimates are imprecise OR
- If it is felt that there is substantial publication bias

Quality ratings are *upgraded* if it is felt that:

- The effect size is large
- If studies are designed in a way that confounding would likely underreport the magnitude of the effect OR
- If a dose-response gradient is evident

Certainty of Evidence

★★★★ High: The authors have a lot of confidence that the true effect is similar to the estimated effect

★★★○ Moderate: The authors believe that the true effect is probably close to the estimated effect

★★○○ Low: The true effect might be markedly different from the estimated effect

★○○○ Very low: The true effect is probably markedly different from the estimated effect

Guideline: Recommendation is from a published guideline that used methodology deemed acceptable by the team

Expert Opinion: Based on available evidence that does not meet GRADE criteria (for example, case-control studies)

Bibliography

Search Methods, End of Life, Clinical Standard Work

Studies were identified by searching electronic databases using search strategies developed and executed by a medical librarian, Susan Groshong. Searches were performed in March, 2018, in the following databases: Ovid Medline, Cochrane Database of Systematic Reviews, Embase, National Guideline Clearinghouse, TRIP and Cincinnati Children's Evidence-Based Recommendations. In Medline and Embase, appropriate Medical Subject Headings (MeSH) and Emtree headings were used respectively, along with text words, and the search strategy was adapted for other databases using text words. Concepts searched were terminal care, passive euthanasia, hospice care, palliative care, advance care planning, end of life, comfort care, life-sustaining care, compassionate extubation and bereavement. Retrieval was limited to 2008 to current, English language, ages 0-24 or family relationships, and to certain evidence categories, such as relevant publication types, index terms for study types and other similar limits.

September 25, 2018

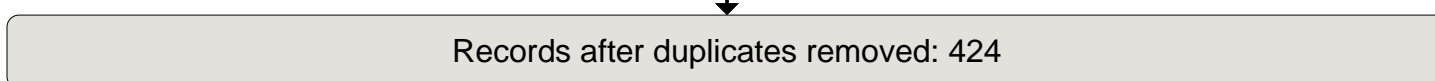
Literature Search PRISMA

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA): a graphical representation of the flow of citations reviewed in the course of a Systematic Review

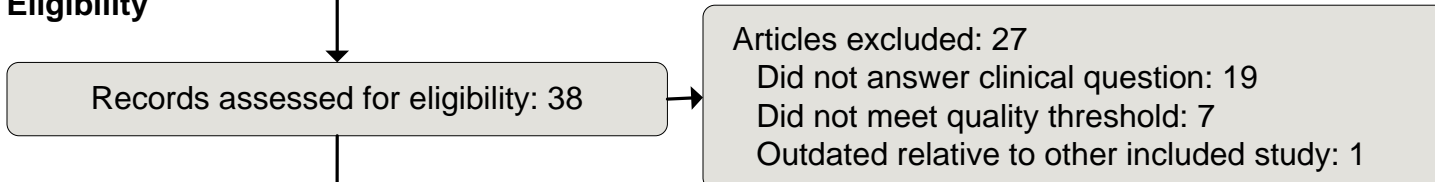
Identification



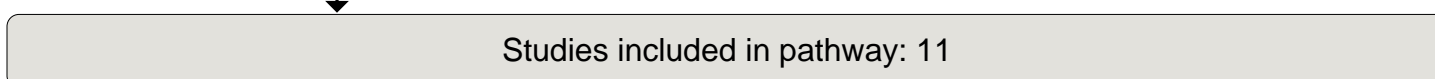
Screening



Eligibility



Included



Flow diagram adapted from Moher D et al. BMJ 2009;339:bmj.b2535

To Bibliography, Pg 2

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Included Studies

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Medical Disclaimer

Medicine is an ever-changing science. As new research and clinical experience broaden our knowledge, changes in treatment and drug therapy are required.

The authors have checked with sources believed to be reliable in their efforts to provide information that is complete and generally in accord with the standards accepted at the time of publication.

However, in view of the possibility of human error or changes in medical sciences, neither the authors nor Seattle Children's Healthcare System nor any other party who has been involved in the preparation or publication of this work warrants that the information contained herein is in every respect accurate or complete, and they are not responsible for any errors or omissions or for the results obtained from the use of such information.

Readers should confirm the information contained herein with other sources and are encouraged to consult with their health care provider before making any health care decision.

