End of Life Care & Bereavement Guide

Pre-Death

Medication

Organ Donation

Post-Death Care Part 1
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.

Post-Death Care Part 2

Tissue Donation

Post-Family Discharge

Staff Support

Decedent Transport

Appendix

Viewing Patients Outside of the Morgue

External Contact Information

Staff Support Questions
End of Life Care v1.2: Pre-Death Care

**Inclusion Criteria**
- Decision to withdraw or limit life sustaining therapies and/or anticipated death during this hospitalization or at home.

**Medical Team**
- May consult the following based on patient and family needs:
  - Palliative Care
  - Pain Service
  - Continuity Provider
  - Primary Care Provider
  - Care Coordination
  - Child Life
  - Art Therapy
  - Music Therapy
  - Spiritual Care
  - Lactation
  - Acupuncture
  - Patient Navigator
  - Interpreter
  - SCAN/CPS

**Medical Team**
- If outside of ICU, consults Palliative Care and Pain Service to assist in developing symptom management plan.

**Multidisciplinary Team Huddle**
- Medical Team, Nurse, Social Work, Patient Navigator (if involved), & Palliative Care (if involved). Others may be included as necessary.
  - Share knowledge of patient and family wishes and preferences
  - Assign roles and tasks to:
    - Initiate End of Life Care Plan
    - Identify patient/family preferences
    - Determine pain and symptom management plan
    - Identify Psychosocial Lead
    - Schedule next huddle

**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
    - Outdoor Options if withdrawal of life-sustaining therapies is requested
  - Sibling Support
  - Travel and lodging needs of family members and support system
  - Autopsy

**Ongoing Multidisciplinary Huddle**
- As needed to:
  - Share knowledge of patient/family wishes & preferences
  - Evaluate effectiveness of pain and symptom management plan and modify as needed
  - Review and update End of Life Care Plan

**Charge Nurse**
- Creates list of continuity nurses
- Consider ways to optimize peaceful environment with current floor dynamics

**Nurse**
- Notifies Unit Coordinators of Patient/Family Visitation Preferences
- Hang Peaceful Environment sign outside room

**Unit Coordinator**
- Updates Epic

**Return to Table of Contents**

For questions concerning this pathway, contact: EoLandBereavement@seattlechildrens.org

© 2020 Seattle Children’s Hospital, all rights reserved. Medical Disclaimer

Last Updated: July 2020
Next Expected Review: November 2023
Inclusion Criteria
- Decision to withdraw or limit life sustaining therapies and/or anticipated death during this hospitalization or at home.
- Patient has died

Medical Team, Palliative Care Provider, Pain Service, and Team Pharmacist (if available) develop and review medication plan outside of ICU

Medical Team
- Notifies inpatient or team pharmacist for situational awareness and identifies an after-hours contact

Inpatient Pharmacist or Team Pharmacist (if available)
- Ensures Omnicell has adequate supply of medication
- Identifies alternative routes for medication, if needed

Nurse
- Notifies Medical Team if patient is requiring multiple medication boluses or if symptoms not well controlled
- Gathers supplies for alternative medications administration routes, as indicated. Alternatives may include: Intra Nasal

Medical Team
- Contacts Palliative Care Provider and/or Pain Service to discuss medication escalation plan, if requiring frequent boluses and/or symptoms not well controlled
- Notify Inpatient or Team Pharmacist if pain/symptoms are worsening and/or frequent medication adjustments anticipated

! If considering withdrawal of fluids, discuss concentrating all medications with pharmacy

! Do not routinely discontinue tone or anti-epileptic medications

! Discuss removing any unnecessary lines, tubes, or drains with family

For questions concerning this pathway, contact: EolLandBereavement@seattlechildrens.org
© 2020 Seattle Children's Hospital, all rights reserved. Medical Disclaimer
Last Updated: July 2020
Next Expected Review: November 2023
End of Life Care v1.2: Organ Donation

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 Procedures Before and After Form

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

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

Is patient a medically suitable candidate for Organ Donation?

- YES
  - 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

- NO
  - Attending, Nurse, Charge Nurse, Social Work huddle with LCNW to make plan for collaborative donation conversation
  - LCNW or affiliate will contact family by phone within 24 hours if patient is eligible for tissue donation

Return to Table of Contents
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.

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

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 End of Life and Bereavement Care Plan
  - 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

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 Care Plan to ensure completion of tasks

For questions concerning this pathway, contact: EoLandBereavement@seattlechildrens.org
© 2020 Seattle Children's Hospital, all rights reserved, Medical Disclaimer
Last Updated: July 2020
Next Expected Review: November 2023
End of Life Care v1.2: Post-Death Care Part 2

Approval & Citation
Summary of Version Changes
Explanation of Evidence Ratings

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

Attending (or delegate)
- Initiate Care Plan, if not already done
- Obtain Death Packet from Unit Coordinator (if not already obtained)
- Complete Cause of Death worksheet (only need date, time and signature for ME Cases or if autopsy is being performed)
- Autopsy Permission/Refusal Form
- Give completed packet to Unit Coordinator
- Notify PCP and Continuity Providers
- Discontinue all ambulatory consults, outpatient prescriptions in CIS
- If inpatient, complete Expiration Summary in CIS
- Contact LCNW within 60 minutes after patient’s death

Psychosocial Lead
- Ensure family follow-up preferences are documented on the End of Life and Bereavement Care Plan

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

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

Social Work (Prior to Discharge)
- Assess family safety & immediate support system
- Complete electronic Journey referral
- Provide family with grief literature, as appropriate, from Unit-Based Journey box

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

When family is ready to leave, escort family to exit

For questions concerning this pathway, contact: EoLandBereavement@seattlechildrens.org © 2020 Seattle Children’s Hospital, all rights reserved. Medical Disclaimer

Last Updated: July 2020
Next Expected Review: November 2023
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

- Contacts LCNW Statline within 60 minutes after death to evaluate for tissue donation suitability
- Records date, time, and contact person on Procedures Before and After Form

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.
# Inclusion Criteria

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

---

**Psychosocial Lead and/or Identified person(s)** follows up with family per End of Life and Bereavement Care Plan

**Medical Examiner Case?**

- **YES**
  - **Attending or delegate**
    - Calls ME to discuss case and cultural considerations **within one (1) business day** if not already discussed
    - Emails executive assistant to Chief Medical Officer to request Autopsy report
  - **NO**

- **AUTOPSY?**
  - **YES**
    - **Attending or delegate**
      - Calls SCH pathologist **as soon as possible** to discuss reason for autopsy and cultural considerations
  - **NO**

**SCH Pathologist**

- Completes Autopsy **within 2 days business days** & will release body to the funeral home
- Completes electronic Death Certificate

**Medical Director**

- Sends autopsy results to Attending

**Attending or delegate**

- Contacts the SCH pathologist if questions regarding the autopsy report (prelim findings available in 2 business days). Final results are typically **received within 2-3 months**
- Contacts primary care provider to review autopsy results and determine if they would like to participate in family follow up

---

**Nurse** notifies Unit Coordinator when family leaves the hospital

**Unit Coordinator** updates EPIC

**Attending or delegate**

- Approve electronic Death Certificate
- Coordinate with Psychosocial Lead and Palliative Care (if involved) to contact family to offer follow-up meeting as documented in the End of Life and Bereavement Care Plan
- Partner with Psychosocial Lead and Palliative Care (if involved) to determine who should attend the meeting and to arrange time and place

---

For questions concerning this pathway, contact: EoLandBereavement@seattlechildrens.org

© 2020 Seattle Children's Hospital, all rights reserved. Medical Disclaimer

Last Updated: July 2020

Next Expected Review: November 2023
Staff Support Pre-Death

Nurse notifies Charge Nurse of anticipated death or limitations in cares.

Charge Nurse & Area Leader huddle to consider:
- Staff support
- Unit support
- Anticipated off-policy request
- Individual RN support
- Family needs

Nurse & Charge Nurse ongoing huddles as needed to assess staff needs.

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

Nursing Leader escalating 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

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.

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 or Attending huddles with resident team as soon as possible.

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

Social Work or Psychosocial Lead identifies funeral home or cemetery that will be receiving patient for immediate burial

Autopsy?

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

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

Attending
Completes Electronic Death Certificate

Funeral Home faxes Burial Transport Permit (BTP) to SCH per the Care at Death, Organ Donation, and Autopsy Policy

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

Family or their agent must physically take the signed Death Certificate and pay fee to the Dept of Vital Statistics:

Deputy Registrar approves, stamps, and signs BTP

Go to Post-Family Discharge

Return to Table of Contents
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.

**Social Work**
- Coordinates with Nurse (or delegate) to assist with family support as available.

**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

**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.

*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.

**Operational Charge Nurse (or delegate)**
- Notify Shift Administrator when patient has been returned to the morgue.

**Nurse (or delegate)**
- Prepares body to return to morgue
- Notify Security that the patient is ready to return to the morgue

**Return to Post-Death Care Part 1**
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
“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.”
End of Life Care & Bereavement Approval & Citation

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

CSW End of Life Care & Bereavement Team

MCC, Pathway Owner: Amber Bock, MSN, ARNP
Patient and Family Relations: Mark Mendelow
Stakeholders:
- Janiine Babcock, MD
- Emily Beauchemin
- Elaine Beardsley, CNS
- Karla Bell, RN
- Julia Besagno, RN
- Zeenia Billimoria, MD
- Brian Cartin, MD
- Jonna Clark, MD, MA
- Martha Dimmers, MDiv, MSW, BCC
- Kelly Dunodon, MD
- Jacob Garrison, PharmD
- Heidi Greider, MDiv
- Melina Handley, ARNP
- Ross Hays, MD
- Sheryl Kalbach, MSW
- Brett Leggett, MD
- Mithya Lewis-Newby, MD MPH
- Emily Loter, MS, PA (ASCP)
- Anne McDermott, ARNP
- Ann McKinstry, RPh
- Trevor McLay, DNP, ARNP
- Jason Orthel, PharmD
- Arika Patneaude, LICSW
- Cassandra Raker
- Melanie Reynolds, MS, RN, CPNP, CHPPN
- Debra Roseberry, MSW, LICSW
- Alice Ryan, MSW
- Karen Taliesin, DMin, BCC
- Neil Uspal, MD
- Hector Valdivia, MN (PCNS)

Clinical Effectiveness Team:

Consultant: Jean Popalisky, DNP
Nurse Consultant: Coral Ringer, MN
Project Manager: Dawn Hoffer
CE Analyst: Maria Jerome
CIS Informatician: Carlos Villavicencio, MD, MMI
CIS Analyst: Wren Haaland, MPH
Librarian: Sue Groshong, MLIS
Program Coordinator: Kristyn Simmons


Please cite as:
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.):

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

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

Expert Opinion – Our expert opinion is based on available evidence that does not meet GRADE criteria (for example, case-control studies).

**Quality of Evidence:**
- ⭐⭐⭐⭐ High quality
- ⭐⭐⭐⭐⭐ Moderate quality
- ⭐⭐⭐ Low quality
- ⭐⭐⭐⭐ Very low quality

Guideline
Expert Opinion
Summary of Version Changes

- **Version 1.0 (11/5/18):** Go Live
- **Version 1.1 (7/1/19):** Added contacts to Internal Contact Information p2; updated Care Coordination tasks to Post-Death Part 2
- **Version 1.2 (7/16/20):** Added Appendix item, Viewing Patients Outside the Morgue
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.
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

Records identified through database searching: 452

Additional records identified through other sources: 0

Screening

Records after duplicates removed: 424

Records screened: 424

Records excluded: 386

Eligibility

Records assessed for eligibility: 38

Articles excluded: 27
Did not answer clinical question: 19
Did not meet quality threshold: 7
Outdated relative to other included study: 1

Included

Studies included in pathway: 11

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


