UCSF Children's Hospital
Neonatal and Pediatric Intensive Care
Compassionate Extubation
Resource Guide

This resource guide is to be utilized in the management of end-of-life care for neonates and children. The withdrawal of artificial life support does not constitute withdrawal of care for patients or their family members. Medical and nursing care are to be continued with the primary focus on the relief of symptoms and provision of comfort, as curative treatments are no longer possible. Emphasis is placed on the quality of life during the dying process and special attention is given to the emotional, psychosocial and spiritual care of patients and their families.

1. This resource guide is intended for use by practitioners in the Neonatal or Pediatric Intensive Care Units: ICN, 6S, 6N, 7E. There may be instances when a patient is moved out of the intensive care unit (ICU) to one of the Comfort Care Rooms; however, ICU staff will continue to care for the patient during and after extubation.

2. This resource guide includes care practices for end-of-life management, including compassionate extubation recommendations.

3. The Do Not Resuscitate (DNR) form is to be completed and signed by the physician, and then placed in the chart. Please refer to the DNR policy for more specific information.

I. Initiate End-of-Life Comfort Measures

1. Promote comfort by discontinuing devices no longer needed such as NG tubes, central lines, extraneous IVs, chest tubes or others (please specify).

2. Review current orders and consider discontinuing laboratory tests, parenteral and enteral feedings, maintenance fluids, blood product infusions, CRRT and diagnostic studies.

3. Discontinue continuous monitoring of all vital signs or limit to monitoring for signs of distress.

4. Discuss with patient and/or family the option of transfer to a Comfort Care Room.

5. All changes in patient care need to be written as medical orders.

II. Review Medication Orders:

1. Reevaluate medications as a result of change in treatment goals and discontinue medications as necessary to maximize comfort and address family goals. Consider discontinuing inotropes, continuous infusions, and scheduled or PRN medications as appropriate. Neuromuscular blocking agents should be discontinued at an appropriate interval (given the medication profile and the child's underlying condition) prior to extubation.[1,2,10] The timing of discontinuing certain medications should take into consideration family readiness and preference for moving to a Comfort Care Room.

2. Initiate or continue medications as needed for comfort, analgesia, and sedation in order to maximize end-of-life comfort. For specific dosing guidelines and information on commonly used medications please consult the Neonatal and Pediatric Palliative Care (Pain and Symptom) Orders.

II. Review Medication Orders (cont.):

3. Consider pain treatment principles:
   - Administer medications continuously or around the clock unless pain is truly intermittent.
   - Always prescribe for breakthrough pain and treat side effects of medications aggressively (except for respiratory depression near time of death).
   - Anticipate and prevent pain when possible, and teach parents to assess pain and expect relief.

4. Reassess pain frequently:
   - Continue to utilize appropriate pain assessment tool for infant or child.
   - Consider parental perception of pain and bedside nurse's assessment of pain.
   - Assess patient's pain level with movement and determine if child can be held without evidence of discomfort.
5. Remember, opioids, particularly morphine, fentanyl and dilaudid, are effective for both pain and dyspnea. Benzodiazepines are effective in reducing anxiety and promoting comfort.[7,9,10]

III. Determine feasibility and family preference for move to a Comfort Care Room

1. Neonatal rooms are located on 15 Moffitt (M1524 and M1506) and are to be used for infants and their families. Contact the L & D (M1524) or ICN (M1506) charge nurse to determine room availability.

2. Pediatric rooms are located on 7 Long (L772, L763, L731) and on 6 North (M628) and can be utilized by any pediatric patient for end-of-life care, including those from the PICU (6S/N) and PCICU(7E). Contact the 7 Long or PICU charge nurse to determine room availability.

3. Families who would like to move to a Comfort Care Room prior to extubating their child may do so. The patient may be moved while on ventilatory and inotropic support when accompanied by an ICU nurse and the medical management is provided by the ICU physicians, respiratory therapist and support staff. Extubation will generally need to occur within a 24 hour period. Staffing the Comfort Care with an ICU nurse must be approved by the home unit's nurse manager.

4. Order Comfort Care basket (beverages and snack foods) from the diet kitchen (353-1345) for the family (after hours contact the nursing supervisor).

IV. Prepare for withdrawal of artificial life support:

1. Explain general steps involved in the compassionate extubation process, confirming if family wants to be present when the ET tube is removed, hold their child, and bathe/dress the child prior to or after extubation.

2. Discuss with family which individuals they would like to be present prior to, during, or after extubation.

3. Explain the dying process and the possibility of irregular respirations that may occur at end-of-life, which may be difficult for family members to watch if they are not prepared. Talk with staff to determine if the family has been offered a very helpful educational booklet (in English or Spanish), Journey Home: Understanding the Final Stages of the Dying Process, which is stocked on all of the units with the other Compass Care supplies.

4. Determine if the family would like keepsakes of their child to be made prior to or after extubation, i.e. hand/footprints, locks of hair or other items for a memory box.

IV. Prepare for withdrawal of artificial life support (cont.):

5. Assemble necessary supplies for making keepsakes, bathing, and dressing wounds and clothing to prepare child before or after withdrawal.
6. Ensure that all necessary medications (including PRN medications) are ordered and in patient's pharmacy profile.
7. Confirm oxygen and suction set-up if moving to a Comfort Care Room.

V. Confirm Psycho-Social Team Involvement

Social Work_____ Child Life_____ Spiritual Care Services_____

VI. Determine Mechanical Ventilation Orders: Terminal Weaning or Immediate Extubation

Terminal weaning refers to a gradual decrease in ventilatory support which allows the airway to be protected, can minimize respiratory distress and diminish air hunger, and can be followed by extubation.[2,3,4,5,10] Opiates and benzodiazepines should be used concurrently to aid in the control of respiratory distress.[2,4,10] Method of withdrawal should be determined by patient need and physician preference.[4,5,6,10]

1. Confirm current ventilatory settings: Mode: _____ Respiratory Rate: _____ CPAP: _____
   Tidal Volume: _____ Pressure Support: _____cm H20 FiO2: _____ PEEP: _____cm H20

2. Consider weaning ventilatory support via the following:[3,6]
   a. Ensure adequate analgesia and sedation for patient prior to weaning of ventilation. Monitor continuously for signs of respiratory distress and medicate accordingly.
   b. Discontinue apnea, heater, and other ventilator alarms in patient room. May choose to continue to monitor patient at nurses station.
   c. Consider reducing FiO2 to .21 over 5 to 10 minutes.
   d. Consider reducing PEEP to 5 cm H2O over 5 to 10 minutes.
   e. Consider weaning respiratory rate to 4 and/or PS to 5 cm/H2O over 5 to 20 minutes to induce CO_2 narcosis.
   f. When it is determined the patient is comfortable, extubate to room air and turn ventilator off.

VII. Palliative Care Resources

Compass Care (Palliative Care) Services:
Robin Kramer, RN 353-4248; 443-4248 Tina Ratto, RN (15L) 443-5191
Helge Osterhold, PhD(c) 443-4073
Pediatric Palliative Care Resource Team:
Sally Sehring, MD (ICN) 443-4299 Stephanie Berman, LCSW (ICN) 443-3971
Judith Laughlin, LCSW (PICUs) 443-3956 Jeff Fineman, MD (PICUs) 443-9511
Tiffany Martorana, MS, CCLS (Child Life 6S) 443-5672/4914

Social Work Services:
ICN: Call front desk at 353-1565 Mon.- Fri. and ask for social worker assigned to family; Weekend coverage: Saturday pager: 443-5948; Sunday pager (urgent needs only): 443-6778
PICU/PCICU: Pager: 443-7931 or 443-3956 Mon.- Fri.; Pager: 443-6778 after 11 am Fri., Sat. and Sun.

Spiritual Care Services: Pager: 443-2273 (443-CARE), available 24 hours a day.

Child Life Services: 353-1203; pager: 443-4914, Monday through Sunday.

Patient Relations: 353-1936, Mon.- Fri. Act as family liaison and assists with questions or concerns related to the "next steps" after a loved one dies (i.e. arrange for release of body to the mortuary, assistance with death certificate). Evenings, weekends and holidays please refer questions to the Nursing Supervisor.

Nursing Supervisor: Pager: 443-6425

References

1. Brody, H, Campbell, ML, Faber-Langendoen, K, Ogle, KS: Withdrawing intensive life-sustaining treatment – recommendation for compassionate clinical management. NEJM 1997; 336: 652-657

2. Burns, JP, Mitchell, C, Outwater, KM, Geller, M, Griffith, JL, Todres, D, Truog, RD: End-of-life care in the pediatric intensive care unit after the forgoing of life-sustaining treatment. Criti Care Med 2000; 28(8): 3060-3066

3. Campbell, ML, Bizek, KS, Thill, M: Patient responses during rapid terminal weaning from mechanical ventilation: a prospective study. Crit Care Med 1996; 27(1): 73-77

4. Faber-Langendoen, K: The clinical management of dying patients receiving mechanical ventilation. A survey of physician practice. Chest 1994; 106: 880-888

5. Gilligan, T, Raffin, TA: Withdrawing life support: Extubation and prolonged terminal weans are inapropriate. Crit Care Med 1996; 24:2: 352-353

6. Meyer, EC, Ritholz, MD, Burns, JP, Truog, RD: Improving the quality of end-of-life care in the pediatric intensive care unit: parents' priorities and recommendations. Pediatrics 2006; 117(3): 649-657.

7. Solomon, MZ, Seller, DE, Heller, KS, Dokken, DL, Levetown, M, Rushton, C, Truog, RD, Fleishchman, AR: New and linger controversies in pediatric end-of-life care. Pediatrics 2005; 116(4): 872-883

8. Treece, PD, Engelberg, RA, Crowley, L, Chan, JD, Rubenfeld, GD, Steinberg, KP, Curtis, JR: Evaluation of a standardized order form for the withdrawal of life support in the intensive care unit. Crit Care Med 2004; 32(5): 1141-1148

9. Truog, R, Meyer, EC, Burns, JP: Toward interventions to improve end-of-life care in the pediatric intensive care unit. Crit Care Med 2006; 34(11): S373- S379

10. Zawistowski, CA, DeVita, MA: A descriptive study of children dying in the pediatric intensive care unit after withdrawal of life-sustaining treatment. Peds Crit Care Med 2004; 5(3): 216-223