UCDAVIS HEALTH | CHILDREN'S HOSPITAL

Pediatric Compassionate Extubation Guidelines

ONLY FOR INFANTS, CHILDREN OR TEENAGERS TRANSITIONING TO COMFORT CARE WITH REMOVAL OF LIFE SUSTAINING THERAPIES

Notify the following of planned or anticipated compassionate extubation at _____Time:

- ☐ Contact Main Information Desk to allow identified visitors/ family to the unit as instructed by Patient Care Unit.
- ☐ Unit respiratory therapist
- ☐ Unit pharmacist
- ☐ ECMO perfusionist (if applicable)
- ☐ Cardiology (if pacemaker/defibrillator in use)
- ☐ Spiritual Care
- ☐ Social Work
- ☐ Child Life
- ☐ STEPS Team if requested by MD/ APRN or STEPS already involved with patient.
- ☐ Genetics (if involved regarding any remaining genetic tests that may need to be done before or after death).
- ☐ PMD and other subspecialist that have been involved in patient's care inpatient and outpatient if appropriate.

PRIOR TO EXTUBATION

Medical Provider

- ☐ Establish which medical provider will be running the removal of life sustaining therapies.
- ☐ Utilize Pediatric Compassionate Extubation Order Sets which includes:
    - DNR order
    - Comfort care instructions
    - Pain and symptom management (Morphine for Dyspnea/Pain, Lorazepam or Midazolam for agitation, Atropine or Glycopyrrolate for excessive oral secretions, etc

- Consults for STEPS team, Child Life, Social Work if indicated.
- Hold feeds and change IVF to TKO for medication administration.
- Ventilator management and extubate orders.

☐ Explain to family End of Life symptoms:
- Breathing patterns and noise of breathing that may occur.
- Secretions and inability to clear deep secretions.
- Changes in color
- Changes in temperature
- If discontinuing nutrition or hydration and death is expected to occur over many days discuss expected change in physical appearance

☐ Discuss autopsy (if applicable), release of remains, genetics and organ/tissue donation.
- **Organ procurement organization should be contacted BEFORE we discuss with the family regarding the plan for redirection to comfort care, so there is a better sense of what could be offered when discussing options with the family prior to death.**
- If autopsy is requested or required (coroner's case) have family **sign consent now, must go with patient to morgue** (policy for availability of autopsy at UCD may vary)
- Discuss any foreign material or lines that will not be able to be removed if autopsy is requested or required.
- If appropriate, discuss that ECMO cannulas generally cannot be entirely removed even if desired by family.

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☐ **Provider managing extubation plan should huddle and review goals with respiratory care practitioner, pharmacist, bedside RN, and any other staff involved with compassionate extubation and ascertain comfort with plan and answer questions**.

☐ A "dry run" of planned extubation in the hallway or empty room with staff involved due to complexity of care, positioning of patient/family and removal of equipment

<u>MEDICATIONS:</u>

☐ Discontinue any medications that are no longer indicated prior to redirection to comfort care.

☐ Develop plan to discontinue pressors and inotropes with nursing.

☐ MEDICATIONS FOR PAIN/DYSPNEA/ANXIETY/AGITATION ARE NOT NEEDED FOR PATIENT'S WITH DIAGNOSIS OF DEATH BY NEUROLOGICAL CRITERIA

☐ **Discuss the need for palliative sedation using propofol or barbiturate infusions if there is concern for refractory symptoms.**

- Regarding patients for Donation after Cardiac Death (DCD): ensure appropriate medications and dosages are available if extubating in PACU

Please ensure all medications ordered in appropriate route and in pyxis:

- **If patient is already on continuous infusions of morphine and/or midazolam, expect to increase current rates by 30% prior to removal of life sustaining therapies and then titrate to effect for comfort.**

- **If opioid and benzodiazepine naïve then would expect to start at 30% of starting doses of each using opioids first line for dyspnea, shortness of breath or discomfort and benzodiazepines for agitation or restlessness.**

PAIN/DYSPNEA

If central line or PIV in place, please consider use of continuous IV infusions if not already in use. (Start 30 minutes ahead)
Morphine drip 0.1 mg/kg/hr increase by 0.05 mg/kg/hr every 15 mins for respiratory distress/dyspnea OR pain

AND for breakthrough dyspnea or pain

Morphine 0.1 mg/Kg IV every 30 min as needed (dyspnea/air hunger)

AGITATION/ANXIETY/RESTLESSNESS OR SEIZURES

If central line or PIV in place, please consider use of continuous IV infusions if not already in use. (Start 30 minutes ahead)
Midazolam Infusion: 0.05 mg/kg/hr and increase by 0.05 mg/kg/hr every 15 minutes for agitation, anxiety or dyspnea.

AND for breakthrough

IF on continuous Midazolam infusion provide; Midazolam 0.1 mg IV every 30 minutes as needed for severe agitation/anxiety/dyspnea or seizures.

OR

Lorazepam 0.1mg/kg IV every 30 mins as needed for severe agitation/anxiety/dyspnea or seizures.

IF PATIENT IS UNABLE TO HAVE IV ACCESS
If Patient has a Feeding tube (NG/GT/SL):

(SL preferred route as gastric perfusion and absorption decreases leading to decreased efficacy of medications)

PAIN/DYSPNEA
Give Morphine 0.3 mg/Kg NG/GT/SL 30 mins before extubation

THEN

Morphine 0.2 mg/Kg sublingual (SL) or NG/GT every 30 min as needed for dyspnea.

AGITATION/ANXIETY
Ativan 0.1mg/Kg NG/SL every 30 mins for agitation

PALLIATIVE SEDATION FOR REFRACTORY SYMPTOMS (REFER TO POLICY #13044)

- Propofol:
    - Continuous IV infusion**:** After Initial bolus of 1-2 **mg**/kg begin continuous infusion at 5 **mcg**/kg/minute; increase by 5 to 10 **mcg**/kg/minute every 5 to 10 minutes until goal sedation level is achieved. Usual maintenance dose: 5 to 50 **mcg**/kg/minute. Maximum dose (not well defined; may vary by institution): 60 to 100 **mcg**/kg/minute
    - Intermittent bolus: Provide 0.25 to 0.5 **mg**/kg (with total max dose 10 to 20 mg) additional doses as needed to achieve adequate sedation

OR

- Pentobarbital
    - Infants, Children, and Adolescents: IV: Loading dose: 2 mg/kg followed by a continuous IV infusion of 1 mg/kg/**hour.**
    - Additional boluses at a dose equal to hourly rate may be given every 2 hours as needed. If ≥4 to 6 boluses are administered within 24 hours, then increase maintenance rate by 1 mg/kg/**hour**; reported required range: 1 to 6 mg/kg/**hour** (median: 2 mg/kg/**hour**).

OR

For NEONATES:

- Dexmedetomidine:
    - If not already utilizing, consider dexmedetomidine infusion 0.2 – 0.7 mcg/kg/hr. Start at 0.2 mcg/kg/hr and increase by 0.1mcg/kg/hr every 15 minutes for respiratory distress/dyspnea or agitation/restlessness

SECRETION MANAGEMENT

- Atropine 1% ophthalmic solution (comfort care drops) sublingual 1-2 drop every 2 hrs as needed for excessive oral secretions distressing to patient.
- Scopolamine patch if able to place 4 hrs prior to extubation and if age appropriate.

If atropine not available or ineffective or unable to utilize scopolamine patch:

- Glycopyrrolate 40 mcg/Kg PO/GT/NG every 4 hrs as needed for increased secretions distressing to patient.
  OR
- Glycopyrrolate 4 mcg/kg IV for increased secretions every 4 hrs as needed for secretions distressing to patient.

Consider the following ventilator management prior to extubation to assess symptom control

- ☐ VENTILATOR WEAN in the following order:
  - Decrease to Room Air
  - Decrease Rate (down to lowest rate of 4 for children and 10 for neonates/infants)
  - Decrease Pressure Control or Tidal Volume by 50%

- ☐ Watch for any worsening dyspnea and provide as needed medications and adjust medications infusions until patient appears comfortable prior to extubating.

Nursing Provider (plan assigned nurse with extra support)

- ☐ Move patient to quiet room if possible or decrease interruptions in patient room.
- ☐ Give opportunity to hold child or lay in bed with child.
- ☐ If parent wants to lay in bed with patient plan to move patient to appropriate bed for size and safety. If possible, move patient to new bed several hours prior to planned extubation
- ☐ Contact Environmental Services if room needs to be cleaned and remove any unnecessary items/equipment to allow for more space.
- ☐ Optimal to discontinue any feedings 1- 2 hours prior to planned discontinuation of life sustaining therapies. Otherwise, discontinue when moving forward with extubation
- ☐ Turn off any unused IV pumps and remove as able.
- ☐ **MEDICATIONS FOR PAIN/DYSPNEA/ANXIETY/AGITATION ARE NOT NEEDED FOR PATIENT'S WITH DIAGNOSIS OF DEATH BY NEUROLOGICAL CRITERIA**
- ☐ If **unable** to bolus medication from infusion pump, nurse should consider obtaining a vial of PRN doses of each comfort medication to be available at the bedside – **note** for shift change RN would need to return unused vial in pyxis and then oncoming RN to re-obtain vial of PRN medications as needed.
- ☐ If on PCA or continuous infusions, nurse should consider ordering 1 additional syringe of each medication 1-2 hours prior to extubation.

- **Discuss the need for propofol or barbiturate if there is concern for refractory symptoms.**
- Discuss if there are any lines/tubes that can be removed or should stay to allow for comfort.
- Discuss timing of discontinuation of vasoactive infusion with the medical provider managing redirection to comfort care.
- Gather any needed supplies (chux, diapers, wipes, towels, blankets) for holding child if desired by family and other needed supplies such as facial tissues and adhesive remover.
- Work with Child life team, social worker and/or chaplain and family to provide any necessary services or tasks prior to redirection to comfort care (see sections for child life, social work and chaplain)
- Discuss the process of extubation, the environment with family members and identify which family will be present.
- Discuss monitoring with medical provider and determine which should continue and which should be discontinued, adjust alarm parameters, and then place in palliative care mode if available on monitor.
- Dim lighting if family desires.
- Offer music either from their personal device, unit ipad and/or music therapist if available.
- Discuss possibility of breast milk donation with mother (if appropriate)
    - Lactation consult/handout
    - If not donating, give stored breast milk to family or get permission to dispose of it

Social Worker OR Nursing if SW not available

- Discuss which family members that will be present (if not already discussed with bedside RN)
- Manage large number of family members.
- Give amenities basket or other comfort items for family to use/offer to get food and provide parking passes if indicated.
- Burial arrangements/Funeral home
- Psychosocial support and bereavement resources

Child Life

- Music and special clothing/blanket
- Photography and Legacy building
    - Ensure family has had time for mementos (hand-prints, foot prints, molds and photography if they wish to have this done while child is still alive).
- Sibling support
- Bereavement Resources

Chaplaincy

- ☐ Baptism, blessing or other religious traditions important to family.

DURING EXTUBATION:

Note: if assigned a specific task related to discontinuation of a piece of equipment, when that piece of equipment is removed from the room the staff person will exit along with equipment and not return to room unless requested to do so.

- ☐ **Bedside RN**: Administer medications as needed per assessment of symptoms.
  - If feeding tube in place aspirate gastric contents just prior to extubation
  - **Ensure all medications that are needed are at bedside:**
    - Opioid for dyspnea, increased work of breathing, facial grimace, pain
    - Benzodiazepine for dyspnea not controlled by opioid, agitation, restlessness, anxiety or seizures.
    - Atropine for distressing secretions

- ☐ MEDICATIONS FOR PAIN/DYSPNEA/ANXIETY/AGITATION ARE NOT NEEDED FOR PATIENT'S WITH DIAGNOSIS OF DEATH BY NEUROLOGICAL CRITERIA

- ☐ **Additional RN**: Silence/ Discontinue all alarms
  - Remove feeding pumps and formula if not already discontinued.
  - Discontinue vasoactive medications at the direction of medical provider managing compassionate extubation.
  - Turn off monitors as directed
  - Remove any extra equipment

- ☐ **RT**: Silence/ Discontinue all alarms (consider extra RT in room at time of extubation)
  - Discuss who will be performing the extubation (if not finalized in previous huddle)
  - Silence, turn off all alarms possible, move ventilator to position that allows for movement around patient/room and remove ventilator if possible after extubation.
  - Taper ventilator if directed as above
    - *clarify with the MD/RN what could trigger an alarm if the patient will not be extubated early on (ie. if patient on CPAP only if you are trying to prevent pulmonary hemorrhage, etc, that an apnea alarm needs to be adjusted)*
  - Suction the endotracheal tube and mouth to assess for secretion burden and clear airway. Advise if medications are indicated to limit secretions.

- No deep suctioning after extubation

Special circumstances: When possible as therapies are removed, pieces of equipment should leave the room as well.

ECMO:

- ECMO cannulas generally cannot be entirely removed even if desired by family.
- Discuss with ECMO team the ability to position patient and for family to hold if possible. Have ECMO perfusionist come to bedside to help navigate patient positioning and consider placing a bridge within ECMO circuit (if not already in place) that can be used to connect cannulae together and then discontinue and remove ECMO circuit

Dialysis:

- Note alarm on CRRT does not silence
- Turn off circuit and remove from room at prior to beginning discontinuation of life sustaining therapies.

Pacemaker:

- Notify cardiologist of need to discontinue pacemaker/defibrillator prior to discontinuation of life sustaining therapies.

Additional Comments:

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<u>AFTER CARE:</u>

- Organ donation – Sierra Donor Services will direct this – if it is solid organs death will be pronounced in OR – otherwise it will happen after child goes to morgue.
- Wash/prepare body/ transport to morgue (families cannot walk to morgue with staff)
  - In some cases, there may be a strict timeline after death and burial that should be coordinated carefully with decedent affairs and identified funeral home.

- ☐ Social Worker to be notified if any further resources are needed.
- ☐ Child Life to be notified if any further resources are needed.
- ☐ Staff to walk family to front of hospital or to vehicle, assist packing belonging.
- ☐ Complete Death Packet at bedside
- ☐ Bereavement Services will follow up with family.

Other resources:

Withdrawal of Life-Sustaining Treatments (childrenshospital.org)

Palliative withdrawal ventilation: why, when and how to do it? (medcraveonline.com)

6-1-2021-UCHealth-Compassionate-Extubation-Resource.pdf (uchealth-wp-uploads.s3.amazonaws.com)

FF #34 Symptom control vent withdrawal.3rd ed (mypcnow.org)

FF #33 Vent withdrawal 1.3rd ed (mypcnow.org)

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