UNC Butterfly Pathway:

Guidelines for Withdrawal of Life Sustaining Therapy in the Pediatric Intensive Care Unit

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Background/Scope of the Problem

In the pediatric intensive care unit (PICU), withdrawal of life-sustaining therapy (WOLST), usually in the form of removal of ventilatory support, is pursued when recovery from serious medical illness is no longer considered an attenable goal. A large body of literature supports the forgoing or withdrawing of life-sustaining therapies in the case of medical futility or anticipated poor quality of life. However, limited guidelines exist to guide the process of WOLST. As a result, the process is highly variable and largely left to individual provider discretion.

Goal of Project

To create standardized approach to withdrawal of life sustaining therapy in the pediatric intensive care units at the University of North Carolina.

Exclusion Criteria

Pathway does not apply to patients who meet criteria for death by neurologic criteria or for patients undergoing organ donation after cardiac death.

Step 1: Planning for WOLST

These interventions should begin approximately 6 hours prior to WOLST in an effort to optimize communication, minimize respiratory distress associated with withdrawal of ventilatory support, and provide anticipatory grief and bereavement support to families. When possible, it is preferable for WOLST to occur during day shift to optimize the availability of medical and psychosocial team members.

Responsible Party	Category	Item
Physician	Medical interventions	Discontinue unnecessary meds, labs, orders, etc. ☐
		Change pH goals as necessary (ECMO) ☐
		Deactivate ICD at _____ ☐
Physician (fellow or attending)	Communication	Inform PICU team members of decision re WOLST ☐
		Notify subspecialists/surgeons of decision re WOLST ☐
		Provide anticipatory counseling to family ☐
		Consider discussion of autopsy ☐
		Consider discussion of funeral home ☐
		Document ACP note in EMR ☐
		Enter DNR/DNI order in EMR ☐
		Consider notifying Honorbridge ☐
		Consider notifying Medical Examiner (if applicable) ☐
Charge RN	Grief support	Liberalize visitor restrictions ☐
Nurse (charge or bedside RN)	Equipment	Obtain palliative bed w/ dark sheets/towels • *Order as soon as WOLST decision made* ☐
		Obtain courtesy cart ☐
	Medical interventions	Discontinue IVF at _____ ☐
		Discontinue enteral feeds at _____ ☐
		Discontinue neuromuscular blockade at _____ • *Generally ~1 hour* • *If renal dysfunction, generally ~6 hours* ○ *Consider reversal if significant* ☐
ECMO specialist	Medical interventions	Slowly decrease sweep on ECMO beginning at _____ • *Increase sedation as needed* ☐
Respiratory therapy	Communication	If on VDR, oscillator, or jet, discuss transition to conventional ventilator ☐
Social worker	Communication	Communication with CPS/DSS (if applicable) ☐
Child Life Specialist	Grief support	Legacy making ☐
Chaplain	Grief support	Spiritual care ☐

Step 2: Team Huddle

The purpose of the team huddle is to ensure that all members of the care team are in agreement with the decision to proceed with WOLST and have a clear understanding of their specific roles and responsibilities in the process. The team huddle should occur immediately prior to WOLST. (More than one huddle may be appropriate if complex case or WOLST occurs in a staged or step-wise manner.)

Attendance required:

- Nursing (charge and bedside RN)
- Respiratory therapist
- PICU attending/fellow/resident
- ECMO technician (if applicable)
- Pharmacist
- Supportive care team (if following)

Attendance optional:

- Primary team/subspecialists
- Child life
- Pastoral care
- Social work (if CPS/DSS, NAT, questions re medical decision-making rights, etc.)

Step 2a: Structure of Discussion:

Purpose	"The purpose of this huddle is to discuss WOLST for patient…"
Reason	"The reason for WOLST is (MSOF, irreversible brain injury, etc.)…"
Mechanism	"The mechanism of WOLST is…" • Terminal extubation • Disconnection from ventilatory support (if tracheostomy) • Discontinuation of pressor support • Clamping or cutting away ECMO circuit
Risk Factors	"Risk factors for refractory respiratory distress following extubation…" • Upper airway obstruction • Pulmonary hemorrhage • Poor pulmonary compliance • Fully intact cognition and difficulty maintaining sedation
Modifications	"Modifications to usual approach of WOLST…" (rare) • Terminal wean with subsequent removal of ETT • Terminal wean without removal of ETT ○ *Removal of ETT not permitted if ME case* • Addition of propofol

Step 2b: Review Checklist:

Category	Responsible Party	Item
Communication	Physician (fellow or attending)	All family members who wish to be present at bedside and ready to proceed with process of WOLST ☐
Equipment	Respiratory therapist	Adhesive remover, suction ☐
		Conventional ventilator (and any additional equipment needed) for transition from VDR, jet, or oscillator ☐
		Trach cap or HME (if trach present) ☐
	ECMO specialist	Towels, tubing clamps, scissors, perfusion adapters with white cap, straight connector, blanket (to cover circuit), sterile towels (if cutting) ☐
Second Check	Bedside RN	Neuromuscular blockade (NMB) discontinued at _____ ☐
		Reversal of NBM administered at _____ ☐
		ICD deactivated at _____ ☐
Standard Medications	Nurse (bedside RN and/or charge RN)	Opioids (3 doses drawn up and in hand) • Morphine (100% hourly infusion rate) • Hydromorphone (100% hourly infusion rate) ☐
		Benzodiazepines (3 doses drawn up and in hand) • Midazolam (100% hourly infusion rate) ☐
Additional Medications	Bedside RN	Ketamine ☐
		Dexmedetomidine ☐
		Propofol ☐
	Respiratory therapy	Racemic epinephrine (PRN stridor) ☐

Step 3: Withdrawal of Life-Sustaining Therapy

a. ECMO

Responsible Party	Steps
PICU fellow and/or attending	Address any questions or concerns with family ☐
Bedside RN and ECMO specialist	Position patient per family preference ☐
Bedside RN	Place monitor in comfort mode ☐
	Bolus dose of opioid +/- benzodiazepine ☐
	Remove NG tube ☐
	Discontinue vasopressors/inotropes ☐
Respiratory therapist	Silence ventilator alarm/put on stand-by mode ☐
	Suction ETT, remove tape using adhesive remover, deflate cuff, and remove ETT • *If tracheostomy: suction, disconnect from ventilator (do not remove trach), place cap vs HME* ☐
ECMO specialists	Clamp or cut away ECMO circuit ☐ • *Family preference and/or specialist decision* ○ *Clamping preferred if anticipated life expectancy very short* • *Cover circuit with blanket* ☐
PICU fellow and/or attending	Monitor for cessation of electric cardiac activity ☐
	Pronounce patient ☐
Bedside RN	Begin post-mortem care ☐

b. Non-ECMO

Responsible Party	Steps
PICU fellow and/or attending	Address any questions or concerns with family ☐
Bedside RN	Position patient per family preference ☐
	Place monitor in comfort mode ☐
	Bolus dose of opioid +/- benzodiazepine ☐
	Remove NG tube ☐
	Discontinue vasopressors/inotropes ☐
Respiratory therapist	Transition to conventional vent if on VDR, oscillator, or jet ☐
	Silence ventilator alarm/put on stand-by mode ☐
	Suction ETT, remove tape using adhesive remover, deflate cuff, and remove ETT • *If tracheostomy: suction, disconnect from ventilator (do not remove trach), place cap vs HME* ☐
PICU fellow and/or attending	Monitor for cessation of electric cardiac activity ☐
	Pronounce patient ☐
Bedside RN	Begin post-mortem care ☐

Step 4: After Care

Responsible Party	Category	Item
All	Communication	Debrief with PICU team ☐ • *Goal: within one hour*
Physician (resident, fellow, or attending)	Communication	Notify Honorbridge ☐
		Notify Medical Examiner (if applicable) ☐
		Notify subspecialists (if applicable) ☐
		Write death note ☐
		Complete death certificate (NCDAVE) ☐
		Complete autopsy paperwork ☐
		Enter "Discharge patient" order in EMR ☐
Any member of care team	Grief support	Accompany family out of hospital ☐

- *Note: Additional policies exist for neonates (family can take the body home if <2 years of age)*

Appendix: Flyer for Feedback on Clinical Pathway

If you were recently involved in a case of withdrawal of life-sustaining therapy in the pediatric intensive care unit, we would appreciate hearing about your experience. Your feedback will be immensely helpful as we develop a clinical pathway to improve this process for patients, families, and clinical staff.

The survey will take 5-10 minutes to complete. You can skip any questions that you do not want to answer. All your answers will be confidential, and data will be reported in aggregate to protect individual responses.

If have questions about the project, please email chabashy@email.unc.edu.

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