eAppendix 1. Forum Participants

Planning Committee

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Participants

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Consultants

Ms. Manon Abud, Facilitator, Hill + Knowlton Canada, Toronto, Ont.

eAppendix 2

Standardized WLSM order set

Preparing for withdrawal of life-sustaining measures (WLSM)

☒ Notify organ donation organization (ODO) of plan to WLSM

☒ Arrange private space for patient and family members, if available

☒ Liberalize visitation

☒ Consult Spiritual Care/Social Work (if desired by patient or substitute decision maker)

☒ Discontinue all previous enteral feeds, medications (except vasoactive and those for pain and symptom management), maintenance IV fluids, blood work, dialysis, and radiographs

☒ Discontinue routine vital sign monitoring

☒ Discontinue neuromuscular blockade (if neuromuscular blocking agents have been used in the past 4 hours, assess train-of-four. If train-of-four is <4/4, consider delaying WLSM or use a modified ventilator weaning)

☒ Confirm do not resuscitate orders are documented

Pharmaceutical management of distress

Pain and dyspnea

☐ **MOR**phine 100 mg in 100 mL 0.9% NaCl infusion at _____ mg/h

- ☐ For pain or dyspnea, give additional **MOR**phine IV bolus of _____ mg q15 minutes PRN (suggest: 2 mg if opioid-naïve or 2x the hourly infusion rate if already receiving a morphine infusion)
- ☐ If patient receives more than 2 boluses in one hour, THEN start an infusion at 2 mg/h or double the current infusion rate. Adjust the bolus dose to 2x the hourly rate.
- ☐ If the pain or dyspnea persists, notify MD

☐ fenta**NYL** 1,000 mcg in 100 mL 0.9% NaCl infusion at _____ mcg/h

- ☐ For pain or dyspnea, give additional fenta**NYL** IV bolus of _____ mcg q5 minutes PRN (suggest: 25 mcg if opioid-naïve or 1x the hourly infusion rate if already receiving a fentanyl infusion)
- ☐ If patient receives more than 2 boluses in one hour, THEN start an infusion at 50 mcg/h or double the current infusion rate. Adjust the bolus dose to 1x the hourly rate.
- ☐ If the pain of dyspnea persists, notify MD

☒ Document on WLSM Documentation Tool (heart rate, respiratory rate and signs and/or symptoms of pain or dyspnea when providing a bolus or adjusting the infusion rate)

Anxiety and agitation

☒ Optimize analgesia prior to adjusting sedation

☐ Midazolam 100 mg in 100 mL 0.9% NaCl infusion at _____ mg/h

(use current dose if patient is already receiving midazolam, but patient may not require sedation)

- ☐ For signs of anxiety or distress, give additional midazolam IV bolus equal to the hourly dose (suggest: 2 mg for patients not receiving an infusion) given q5 minutes PRN
- ☐ If the patient receives more than 2 boluses in one hour, THEN start an infusion at 2 mg/h or double the current infusion rate
- ☐ If the anxiety or agitation persists, notify MD

☐ Propofol 10 mg/mL premixed vial, infusion at _____ mg/kg/h

(use current dose if patient is already receiving propofol, but patient may not require sedation)

- ☐ For signs of anxiety or distress, give additional propofol IV bolus (suggest: 10-20 mg for patients not receiving an infusion) given q5 minutes PRN
- ☐ If the patient receives more than 2 boluses in one hour, THEN start an infusion at 0.5 mg/kg/h or double the current infusion rate
- ☐ If the anxiety or agitation persists, notify MD

☒ Document Richmond Agitation-Sedation Scale (RASS) score and assess for signs and/or symptoms of anxiety pre and post each bolus dose or rate adjustment

Additional medications

☐ Metoclopramide 10 mg IV q6h PRN for nausea

☐ Glycopyrrolate 0.4 mg IV q4h PRN for oral secretions

Withdrawal of physiologic support

When the family is ready for withdrawal of life support:

☒ Deactivate defibrillator and discontinue transvenous or transcutaneous cardiac pacing

☒ Deactivate mechanical hemodynamic support, aortic balloon pump, ventricular assist device, ECMO

☒ Discontinue all vasoactive medications

When the patient is unresponsive to verbal stimuli (RASS -4 or -5) and signs of respiratory distress (accessory muscle use, tachypnea, nasal flaring) are managed:

☒ Discontinue respiratory support

For patients mechanically ventilated:

☐ RRT to discontinue mechanical ventilation. Choose one of the following options:

- ☐ Rapidly wean ventilator to FiO2 0.21l, PEEP 5cm H20, PS 5cm H20. If patient is comfortable on minimal settings for 5 minutes, extubate to room air.
- ☐ Extubate to room air
- ☐ Other: _____

For patients on non-invasive ventilation or oxygen therapy:

☐ RRT to discontinue non-invasive ventilation or oxygen therapy and place on room air

eAppendix 3

WLSM checklist

Review checklist with team early, in advance of initiating withdrawal of life-sustaining measures (WLSM).

Decision making and documentation

	Action	Notes
☐	The patient's capacity to make decisions and legally correct substitute decision maker has been recorded.	
☐	A multidisciplinary team meeting has occurred and the outcome has been documented in the medical record. Any consulting services with a pre-existing or close relationship (e.g. surgical services, oncology) were involved in the meeting or the decision.	
☐	The plan of care has been documented in the chart and the patient, where possible, and family is aware of this plan.	
☐	An order to WLSM and an order not to provide cardiopulmonary resuscitation upon death is recorded in the chart.	
☐	A description of WLSM has been provided to the family and translation offered, where required.	

Preparing for WLSM

	Action	Notes
☐	Liberalized family visiting has been offered and, where possible, a space for the family to gather privately has been arranged. The family has been offered an opportunity to participate in patient care during WLSM.	
☐	The organ donation organization (ODO) has been notified of the patient's imminent death.	*Notification* to ODO prior to a planned withdrawal of life support conversation. *Referral* to ODO for collaborative planned approach should occur after the decision to WLSM.
☐	Ensure patient and/or family have been offered the opportunity to donate organs and tissues according to regional best practice.	The inter-professional team members will jointly develop a plan for approaching and discussing donation options.

Consultative supports

	Action	Notes
☐	Spiritual care, religious and culture supports are offered, including involvement of the patient's own clergy.	
☐	The opportunity for social/religious/cultural observances has been offered, including an attempt to accommodate any last wishes of the patient.	
☐	A social work consultation has been considered and offered, where appropriate.	
☐	Respiratory therapist is aware of WLSM plans.	
☐	Palliative care consultation is considered and offered, where appropriate.	
☐	***For DCD cases:*** Where indicated, the Coroner or Medical Examiner service has been contacted, role explained to the family and appropriate authorization for donation obtained prior to WLSM.	

Family and team review

	Action	Notes
☐	WLSM order set completed by physician and placed on the chart. An approach for modification of these orders following WLSM is reviewed with the nurse, physician and respiratory therapist to ensure clear approach when the ordered medications fail to obtain goals.	
☐	The specific goals of symptom management are reviewed.	
☐	Approach to symptom management reviewed with health care team, including: • possible symptoms which may occur after WLSM • medications used to treat possible symptoms • medication used to treat any anticipated symptoms not yet present	
☐	Orders reviewed. ICU nurse, respiratory therapist and other team members who will be present during WLSM are comfortable with treatment plan.	
☐	Orders written for discontinuation of all non-comfort medications, blood transfusions, dialysis, vasopressors/inotropes, nutrition, antibiotics, intravenous fluids and laboratory work.	
☐	Orders written for pace and sequence of WLSM, including mechanical ventilation and artificial airway.	
☐	The offer is made to have family present for WLSM and end-of-life care.	

☐	The room preparation and location of WLSM is reviewed and planned, including removing as much equipment and technology as possible from the room. Ambiance room setup preferences are considered.	
☐	Approach to monitoring has been reviewed with the family and healthcare team. Monitoring flowsheet at bedside.	
☐	Team huddle occurs prior to withdrawal of life support and this includes the family, ensuring everyone understands their roles and actions that will occur prior to and following death.	
☐	Post an unobtrusive signal to other ICU team members that WLSM is occurring.	

During withdrawal of life support

	Action	Notes
☐	Symptom management is provided according to the order set and documented on the WLSM documentation tool.	

Donation after circulatory determination of death ONLY

	Action	Notes
☐	The necessity of monitoring for DCD death declaration is reviewed with the family.	
☐	Procedure for death declaration (an organ and/or tissue donation, where required) has been reviewed.	
☐	The possible outcomes, including not dying in a manner which allows organ donation are reviewed.	Patients and families are reminded the gift of life is given in the decision to donate.
☐	The administration of heparin for DCD, where applicable, has been reviewed, including consent, and a dose has been ordered in consultation with the organ donation organization (ODO).	

Registered Nurse:

Name	Signature	Date YYYY / MM / DD

Physician

Name	Signature	Date YYYY / MM / DD

eAppendix 4

WLSM documentation tool template

DATE INITIATED YYYY / MM / DD	TIME INITIATED :	FOLIO ___ of ___	PATIENT IDENTIFICATION

Withdrawal of life-sustaining measures symptom based critical care

Instructions for Use

1. This is a template for a nursing documentation tool to chart events, vitals, and medication administration from the time of withdrawal of life-sustaining measures (life support) and death, transfer to a unit outside the ICU or when 12 hours has lapsed. This template may be used, or it may inform the development of a similar organizational tool for your local unit. Units may want to consider the use of additional RT and or MD documentation tools.
2. Once this document is invoked, a notation in the usual ICU charting document (flowsheet or electronic charting) should be made to indicate that WLSM flowsheet charting has been initiated – e.g. "See WLSM flowchart".
3. If a patient remains alive for an extended period of time following WLSM, usual charting is resumed and a notation should be made in both this flowchart and the usual chart to indicate the transition – e.g. "WLSM flowsheet ended".
4. The minimum charting requirements are as follows:
   a. vital signs are charted just prior to withdrawal and then hourly for the next 12 hours;
   b. rationale for any bolus medication or change in infusion rate is included;
   c. action plans (as detailed in the orders) should be copied on to page 2 of this document prior to withdrawal; and
   d. time of death, declaring providers, and method of declaration must be charted on page 3.
5. If a symptom (listed A-K) is used to justify a bolus or infusion rate change, the letter corresponding to the symptom should be circled.
6. If additional narrative charting is necessary and does not fit on the flow chart, a number can be written and circled to indicate the reader should review the continuation of the note on page 3 of this document.
7. Symptom documentation supports ease of use and compliance. However, the use of validated scales such as BPS, CPOT and RDOS would provide additional value and more objective data. Programs should consider the use of validated scales.
8. Samples of pain, sedation and respiratory scales have been attached as an appendix on page 4.

Pre-WLSM Huddle

Date initiated	YYYY / MM / DD
Time	:
Attending	☐ MD ☐ RN ☐ RT ☐ Spiritual care

Item	Stopped at		Initials
	Date	Time	
Vasoactive agents / pressors	YYYY / MM / DD		
Extubation	YYYY / MM / DD		
Other	YYYY / MM / DD		

WLSM Initiated

Date	YYYY / MM / DD
Time	:

PATIENT IDENTIFICATION

Time	Provider Initials	Vitals			Pain, Dyspnea and Discomfort Management Narcotic: _____ ***Note:*** *The Behavioral Pain Scale (BPS) and the Critical-Care Plan Observation Tool (CPOT) are valid and reliable and could be substituted*			Agitation and Anxiety Benzodiazepine / Anxiolytic				Response to changes in drug administration, sedation/pain meds and other comments
		HR	RR	BP	Respiratory Distress & Air Hunger A. Fearful facial expression B. Accessory muscle use C. Paradoxical breathing D. Nasal flaring E. Family concern	Pain and Discomfort F. Diaphoresis G. Rigidity H. Wincing I. Shutting of eyes J. Clenched fists K. Verbalizing / Moaning	Infusion Rate	Bolus Dose	RASS or SAS	Other	Infusion Rate	Bolus Dose
					A B C D E F G H I J K							
					A B C D E F G H I J K							
					A B C D E F G H I J K							
					A B C D E F G H I J K							
					A B C D E F G H I J K							
					A B C D E F G H I J K							
					A B C D E F G H I J K							
					A B C D E F G H I J K							
					A B C D E F G H I J K							
					A B C D E F G H I J K							
					A B C D E F G H I J K							
					A B C D E F G H I J K							
					A B C D E F G H I J K							
					A B C D E F G H I J K							

☐ Continued in Folio

DATE OF DEATH	TIME OF DEATH
YYYY / MM / DD	:
DEATH WAS PRONOUNCED BY: PHYSICIAN 1	PHYSICIAN 2
OTHER NOTES	

PATIENT IDENTIFICATION

***** The below table refers to numbered charting notes from page 2 of this document. *****

#	Note	#	Note
1		13	
2		14	
3		15	
4		16	
5		17	
6		18	
7		19	
8		20	
9		21	
10		22	
11		23	
12		24	

Post-WLSM huddle

Date initiated	YYYY / MM / DD
Time	:
Attending	☐ MD ☐ RN ☐ RT ☐ Social work ☐ Spiritual care ☐ Other

Charting healthcare practitioners

Initials	Name	Designation

Examples of pain and sedation scales

Richmond Agitation-Sedation Scale (RASS)

Scale	Label	Description	
+4	COMBATIVE	Combative, violent, immediate danger to staff	VOICE
+3	VERY AGITATED	Pulls to remove tubes or catheters; aggressive	
+2	AGITATED	Frequent non-purposeful movement, fights ventilator	
+1	RESTLESS	Anxious, apprehensive, movements not aggressive	
0	ALERT & CALM	Spontaneously pays attention to caregiver	
-1	DROWSY	Not fully alert, but has sustained awakening to voice (eye opening & contact >10 sec)	
-2	LIGHT SEDATION	Briefly awakens to voice (eyes open & contact <10sec)	
-3	MODERATE SEDATION	Movement or eye opening to voice (no eye contact)	
→ If RASS is ≥ -3 proceed to CAM-ICU (is patient CAM-ICU positive or negative?)			
-4	DEEP SEDATION	No response to voice, but movement or eye opening to physical stimulation	TOUCH
-5	UNAROUSABLE	No response to voice or physical stimulation	
→ If RASS is -4 or -5 → STOP (patient unconscious), RECHECK later			

Sessler, et al. Am J Respir Crit Care Med 2002. 166: 1338-1344 Ely et al. JAMA 2003.286. 2983-2991

Riker Sedation-Agitation Scale (SAS)

Score	Term	Descriptor
7	Dangerous Agitation	Pulling at ET tube, trying to remove catheters, climbing over bedrail, striking at staff, thrashing side-to-side
6	Very Agitated	Requiring restraint and frequent verbal reminding of limbs, biting ETT
5	Agitated	Anxious or physically agitated, calms to verbal instructions
4	Calm and Cooperative	Calm, easily arousable, follow commands
3	Sedated	Difficult to arouse but awakens to verbal stimuli or gentle shaking, follows simple commands but drifts off again
2	Very Sedated	Arouses to physical stimuli but does not communicate or follow commands, may move spontaneously
1	Unarousable	Minimal or no response to noxious stimuli, does not communicate or follow commands

Behavioral Pain Scale (BPS)

Item	Description	Score
Facial expression	Relaxed	1
	Partially tightened (e.g. brow lowering)	2
	Fully tightened (e.g. eyelid closing)	3
	Grimacing	4
Upper limb movement	No movement	1
	Partially bent	2
	Fully bent with finger flexion	3
	Permanently retracted	4
Compliance with mechanical ventilation	Tolerating movement	1
	Coughing but tolerating ventilation for the most of time	2
	Fighting ventilator	3
	Unable to control ventilation	4

*Note: BPS score ranges from 3 (no pain) to 12 (maximum pain).

Respiratory Distress Observation Scale (RDOS)

Variable	0 pts	1 pt	2 pts
Heart rate per minute	< 90	90 – 109	> 109
Respiratory rate per minute	< 19	19 – 30	> 30
Restlessness: non-purposeful movements	None	Occasional, slight	Frequent
Accessory muscle use: rise in clavicle during inspiration	None	Slight	Pronounced
Paradoxical breathing	None	-	Present
Grunting at end-expiration: guttural sound	None	-	Present
Nasal flaring: involuntary movement of nares	None	-	Present
Look of fear	None	-	Eyes wide open, facial muscles tense, brow furrowed, mouth open

Journal of Palliative Medicine. 2010; 13(3): 285-290

Critical-Care Pain Observational Tool (CPOT)

Indicator	Score		Description
Facial expressions	Relaxed, neutral	0	No muscle tension observed
	Tense	1	Presence of frowning, brow lowering, orbit tightening and levator contraction or any other change (e.g. opening eyes or tearing during nociceptive procedures)
	Grimacing	2	All previous facial movements plus eyelid tightly closed (the patient may present with mouth open or biting the endotracheal tube)
Body movements	Absence of movement or normal position	0	Does not move at all (doesn't necessarily mean absence of pain) or normal position (movements not aimed toward the pain site or not made for the purpose of protection)
	Protection	1	Slow, cautious movements, touching or rubbing the pain site, seeking attention through movements
	Restlessness/Agitation	2	Pulling tube, attempting to sit up, moving limbs/thrashing, not following commands, striking at staff, trying to climb out of bed
Compliance with the ventilator (intubated patients) OR Vocalization (extubated patients)	Tolerating ventilator or movement	0	Alarms not activated, easy ventilation
	Coughing but tolerating	1	Coughing, alarms may be activated but stop spontaneously
	Fighting ventilator	2	Asynchrony: blocking ventilation, alarms frequently activated
	Talking in normal tone or no sound	0	Talking in normal tone or no sound
	Sighing, moaning	1	Sighing, moaning
	Crying out, sobbing	2	Crying out, sobbing
Muscle tension Evaluation by passive flexion and extension of upper limbs when patient is at rest or evaluation when patient is being turned	Relaxed	0	No resistance to passive movements
	Tense, rigid	1	Resistance to passive movements
	Very tense or rigid	2	Strong to passive movements or incapacity to complete them
Total		/ 8	

*Note: When a patient's CPOT is >3, the team will evaluate pain sources and modify/enhance pain management. CPOT sensitivity = 86% and specificity = 78% (Gélinas C, J Pain Sympt Man 2009).

Adapted from Gélinas et al., AJCC 2006; 15(4):420-427). Reproduced with permission. For more information about the CPOT use, contact the author at celine.gelinas@mcgill.ca

eAppendix 5

WLSM family information

What does it mean to withdraw life-sustaining measures or life support?

Your care team is there to help you and your loved one. However, when a patient is very ill, the care team cannot always help them get better despite their best treatments, efforts and hopes. In these situations, the aim is to keep your loved one comfortable while allowing them to die with dignity and respect.

Withdrawal of life-sustaining measures involves several steps, throughout which respect, dignity and your loved one's comfort is the care team's main priority. When the decision is made to withdraw life support and allow death to occur, you can expect the following to take place:

- Medications that control blood pressure or heart rate will be stopped
- The ventilator (breathing machine) will be turned off and the breathing tube is usually removed
- If your loved one is on dialysis, it will be discontinued
- The vital signs monitor may be turned off; staff will watch your loved one for comfort rather than checking his or her vital signs
- Routine tests like blood work and X-rays will no longer be ordered
- Intravenous fluids will be decreased or stopped
- Tube feeding will be stopped and the feeding tube may be removed
- Any treatments or medications that are not aimed at treating symptoms, increasing comfort, maintaining dignity or supporting cultural-social well-being will also be stopped

Adjustments may occur to meet the needs of your family and your loved one. Your care team will discuss these steps with you in more detail.

What can I expect after life support is withdrawn?

It is difficult to predict when death will occur. In some cases, it comes quickly. In other circumstances, it may occur several hours or even days after life support is withdrawn. Regardless of the amount of time before death, your loved one will continue to receive care.

What symptoms could my loved one experience and how will these be treated?

Your loved one will be closely watched for signs of pain or distress. If you notice any change that concerns you, tell a member of your care team.

Pain and shortness of breath:

- Pain may cause changes in facial expression, agitation, or other signs of discomfort. Pain will be treated with medications like morphine which can be quickly adjusted to ensure comfort.
- Shortness of breath may occur, particularly as the breathing machine is turned off and the breathing tube removed. Medications are given to ensure that your loved one is comfortable.

- When pain and shortness of breath are treated with medication, the dose given will be based on the amount of comfort medication your loved one is already receiving. Studies have shown that giving medication for comfort does not shorten life. There is no reason to over treat or undertreat pain or shortness of breath.

Changes in breathing pattern:

- You may notice pauses in breathing, snoring, or rapid shallow breathing. This is a normal part of the dying process and not necessarily a sign of discomfort. It generally does not need to be treated.
- Changes in swallowing may cause saliva to pool at the back of the mouth and cause a rattling or gurgling noise when your loved one breathes. This is likely not uncomfortable for your loved one. However, medications and treatments may be given if it causes discomfort.

Anxiety and agitation:

- Signs of agitation can include restlessness, frequent movements, or pulling at blankets and tubes. Your loved one will be watched closely for these symptoms and provided sedative medications as needed.

Hunger and thirst:

- At end-of-life, most people do not feel hungry or thirsty. As the body's systems begin to shut down it can become difficult for people to tolerate food and fluids. For this reason, stopping fluids and tube feeding during this time is recommended. Some people experience discomfort from dry lips or a dry tongue. This is best treated with moist swabs or an artificial saliva spray rather than giving fluids intravenously.

How can I support my loved one during this time?

You are welcome to be in the room as life support is stopped. This is a very personal decision. Some families and family members prefer to be present and others do not. Your health care team will support any decision you make. Simply sitting with your loved one, speaking quietly with them, and holding their hand can help to provide comfort.

If you would like to bring in items like photos, music, and letters from friends and family to celebrate the life of your loved one, you may do so. If there are cultural or religious rituals that are important to your loved one, you may bring in your own spiritual leader or ask your care team to help arrange this.

What if I need support?

During this time, you may have many different feelings such as sadness, anger, fear, guilt, or even relief. It can be helpful to talk with the friends and family members about your feelings and fears. All members of your health care team, including the doctors, nurses, respiratory therapists, social workers and spiritual care providers are there to support you during this very difficult time. If you would like some time alone, there are spaces in the hospital for quiet reflection or prayer.

Community resources are available to support your family during and after the end-of-life process. Your care team can provide more information on what support is available.

If I have questions, who can I ask?

If you are concerned about your loved one's comfort at any time or have questions about their symptoms and how they are being treated, please let a member of your care team know. Sometimes it helps to write down questions or concerns.

There are many members of the team caring for your loved one. With around-the-clock care, you may meet doctors, nurses, and respiratory therapists who will become new members of your care team. Feel free to ask questions and introduce yourself. Your care team is there to support you and your family throughout end-of-life care.

What if our loved one wanted to be an organ or tissue donor?

Organ and tissue donation may be an option following death. Experts in organ and tissue donation are available to answer questions and support you and your family through the donation process. Your care team may raise the issue of donation with your family. Please feel free to talk to your team about organ and tissue donation.

If your loved one wishes to donate his or her organs and or tissues, the timing for withdrawal of life support will be discussed. The organ and tissue donation teams and the physicians from the intensive care unit will be a part of the discussion with you and your family. All teams and team members will ensure your loved one is comfortable. The medications they receive for comfort will not change.

Additional medications and tests may be required. If so, the organ donation coordinator will discuss this with you.

You will be able to be with your loved one when life support is removed. Vital sign monitors will remain in place. When your loved one dies, two physicians will confirm that death has occurred. Your loved one will then be moved to the operating room for donation. If you wish to be with your loved one after organ donation has taken place that can be arranged.

Even if your loved one wished to be an organ donor, donation may not always be possible. The dying process is unpredictable and may take longer than expected. In some cases, your loved one's organs may not have received enough oxygen to work well for someone else. It is important to remember the gift of life is in the decision to donate. We recognize the potential disappointment when organ donation is not possible and will do all we can to support you through this.

The timeline for tissue donation is different from organ donation and may occur within 24 hours of death.

Staff from the intensive care unit and the organ and tissue donation teams will be available to answer any questions you may have. If you wish to discuss organ donation or your decision to do so, please ask to speak to a member of your care team at any time.

Questions?

You may still have questions about what happens at end-of-life. Sometimes it helps to write down your questions. Please don't hesitate to ask questions and raise any concerns you may have with any member of your care team. Your care team is there to support you, your loved one and your family through this difficult time.

eAppendix 6

WLSM system audit

DATE YYYY / MM / DD	HOSPITAL NAME	UNIT

The purpose of this audit is to enhance the quality of the process of withdrawal of life-sustaining measures (WLSM) in special care units where life support measures are used. Intensive care units (general or specialized), cardiac care units, high acuity units, step-down units, etc. Please note that this applies to the **clinical** process of WLSM, and NOT the decision-making process.

As a unit, your task is to document whether you have the following best practices in place in advance of WLSM from a patient. A comment section is available for your use. **Please comment on any "No" answers**. These are based on the Canadian Critical Care Society's Guidelines on Withdrawal of Life-Sustaining Measures.

To be completed by Physician and Administration lead for the unit, in consultation with front line staff.

Policy and procedure background work

Policy and Procedure	Yes	No	Comments
Does the organization have a specific policy on WLSM?			
Does the policy reference the CCCS Guidelines on WLSM?			
Does the organization have an organ and tissue donation committee?			
Has the donation committee reviewed the CCCS guidelines for WLSM and local policy, if present?			
Does the organization routinely evaluate or audit cases of WLSM? If yes, is there a case audit tool?			
Is there a process in place to assess and communicate audit results at defined intervals? • someone responsible to conduct audits • person responsible to analyze and provide feedback • person responsible to act on results			
Is there a process to develop an inter-professional care plan for WLSM for each patient? (e.g. mandatory huddle to discuss roles and responsibilities)			
Are there regular education sessions on staff roles in WLSM for:			
• physicians			
• nurses			
• RTs			
Please check yes/no for each and comment on frequency.			
Notes: *(any missing item should be addressed in the action plan below)*			

Preparing for WLSM

Preparing for WLSM	Yes	No	Comments
Can the unit provide a private room for patients at end-of-life? *If yes, please comment on frequency (e.g. always, usually, sometimes).*			
Is there a separate family room for family to gather, particularly if their loved one is at end-of-life? *If yes, please comment on frequency (e.g. always, usually, sometimes).*			
Are there environmental aids (e.g. signs) identifying, in an unobtrusive way, the process of WLSM has started (facilitates liberal visiting, etc.)?			
Is acute grief support available for families? *If so, please specify who provides this.*			
Are families welcome to be present for WLSM and participate in the patient care before, during and after?			
For challenging or complicated cases, practitioners are encouraged to seek advice and support from colleagues.			
Notes: *(any missing item should be addressed in the action plan below)*			

Assessment of distress during WLSM

Assessment of distress during WLSM	Yes	No	Comments
Is there a specific documentation tool for documenting symptoms and treatment of symptoms in WLSM?			
Are standardized scoring systems or some objective measure of assessment embedded in this documentation for:			
• pain			
• respiratory distress			
• agitation			
• delirium			
Please check yes/no for each.			
Is there education for staff to ensure families can also contribute to the assessment of symptoms at end-of-life?			
Notes: *(any missing item should be addressed in the action plan below)*			

Discontinuation of treatment and monitoring

Does the unit have the following materials available?	Yes	No	Comments
Guideline and/or clinical protocol for WLSM process (step-by-step procedure)			
Checklist to support the WLSM process in real time with each patient			
Pre-printed standardized orders for WLSM			
Educational material for staff for WLSM process			
Educational material for family for WLSM process			
Documentation tools for WLSM process			
Notes: *(any missing item should be addressed in the action plan below)*			

Following WLSM and patient death

Are the following in place?	Yes	No	Comments
Bereavement material available for family			
Family satisfaction with WLSM survey. *If yes,* • *how frequently is it done?* • *who sends out surveys?* • *who analyzes results of surveys?*			
Process for staff debriefing after WLSM *If yes,* • *is it formalized?* • *who decides on need for debrief?* • *who conducts debrief?*			
Notes: *(any missing item should be addressed in the action plan below)*			

System audit follow up action items and accountability

ACTION ITEM	ACCOUNTABILITY

PERFORMED BY	DATE YYYY / MM / DD	TIME :

System audit tool helped facilitate discussion: ☐ Yes ☐ No

Tool requires revision: ☐ No ☐ Yes – Feedback provided to_____

A repeat system audit will be completed for this unit in _____ months (suggest: 12)

eAppendix 7

WLSM case audit

DATE WLSM STARTED YYYY / MM / DD	IDENTIFIER 1	IDENTIFIER 2
NAME	MRN	☐ DCD ☐ No donation

Cause of Death/Decision for WLSM: _____

Event timing

Event	Time	Comments
Withdrawal of vasopressors	Start : Complete :	
Withdrawal of mechanical ventilation	Start : Complete :	
Withdrawal of supplemental oxygen	Start : Complete :	
Extubation	:	
Death	Date / Time YYYY/MM/DD :	
Transfer from unit prior to death. *If yes, document date and time.*	☐ No ☐ Yes Date / Time YYYY/MM/DD :	
Bedside monitors	☐ ON ☐ OFF	
Notes: *(any missing item should be addressed in the action plan below)*		

Preparation for WLSM

Location of documentation sough in the audit predefined by site. Do not include items suggested below if not routinely documented at your site. Location can be in nursing or physician's notes or use of specific checklist completed for WLSM. A checklist is strongly recommended where items match the audit.

Which of the following are clearly ***documented***?	Yes	No	Comments
Multidisciplinary care plan for WLSM			
Notification of Organ Donation Organization			
Patient/family offered the opportunity for organ and tissue donation			
Pre-WLSM huddle of physician, RN, RT, social work, others			
Explicit decision made regarding use of bedside monitors and in consultation with family			
Signal/sign posted that WLSM is occurring			
Spiritual/culture needs of patient and family discussed prior to WLSM			
Spiritual/culture support offered to patient and family			
Family encouraged and permitted to participate in patient care before, during and after WLSM			
Notes: *(any missing item should be addressed in the action plan below)*			

Process of WLSM

Steps	Yes	No	Comments
Family present during WLSM			
Concern noted regarding RN availability during WLSM			
Concern noted regarding RT availability during WLSM			
Concern noted regarding MD availability during WLSM			
Standardized order set available and signed in advance of WLSM *Check documented times.*			
Notes: *(any missing item should be addressed in the action plan below)*			

Assessment of distress and symptom relief during WLSM

It is assumed each unit will use only one scoring system for symptoms.

Is the following documented in the RN notes?	Consistently	Inconsistently	Not at All	Comments
Pain score used				
Sedation score used				
Respiratory distress score used				
Delirium score used				
Medication name(s) and dose(s) used to treat anticipated symptoms with documented rationale				
For evident symptoms, administration of medication included documentation of:	**Consistently**	**Inconsistently**	**Not at All**	**Comments**
• score prompting use of medications				
• dose				
• response				
Notes: *(any missing item should be addressed in the action plan below)*				

Following death

The following items are suggestions. Documentation must be clear and a post WLSM checklist matching the items below is suggested.

Follow up	Yes	No	Comments
Grief literation/information/support offered to family			
Referral to community bereavement support			
Suggestion whether to review case documented			
Notes: *(any missing item should be addressed in the action plan below)*			

Case audit follow up action items and accountability

ACTION ITEM	ACCOUNTABILITY

PERFORMED BY	DATE YYYY / MM / DD	TIME :

Case audit tool helped facilitate discussion: ☐ Yes ☐ No

Tool requires revision: ☐ No ☐ Yes – Feedback provided to_____

WLSM policy

Withdrawal of life-sustaining measures (WLSM)

The inter-professional team's primary responsibility is to ensure that decisions are being made in the best interests of the patient which should be guided by the following principles:

- to honor the patient's wishes at end-of-life;
- to offer care that is collaborative with a shared-decision making model;
- to support family/substitute decision maker (SDM) during the difficult decision-making process;
- to align evidence-based interventions with the patient and family's values, beliefs and goals;
- to alleviate suffering and prevent harm; and
- to communicate clearly and respectfully with the patient, family and inter-professional team.

Prior to WLSM, an inter-professional care plan should be created for each patient focusing on symptom management, order and pace of withdrawal, and family support. Referral to an organ and tissue donation program, if appropriate, should also be initiated.

WLSM should be carried out in accordance with the 2016 Canadian Critical Care Society's Guidelines, and applied in accordance with the following principles, while respecting the needs and wishes of patients and their families.

The principles of expert inter-professional critical care must foster a seamless transition into end-of-life care. It is imperative that end-of-life care in the critically ill be of the highest quality, in all circumstances, including that of organ and tissue donation.

High quality end-of-life care:

- maintains dignity, respect and compassion;
- explores the wishes and voices of the patient and family/SDM;
- respects cultural, spiritual values and observances;
- continues to support and partner with patients, families/SDM and health care team members throughout the death experience;
- is consistent with guidelines for WLSM;
- focuses on alleviating pain, distress and providing comfort;
- adheres to the existing medicolegal framework that includes respect for the dead donor rule and precludes intentional hastening of death (notwithstanding medical assistance in dying legislation);
- avoids unnecessary prolongation of the dying process; and
- preserves the opportunity to donate organs and tissues.

These principles of person-centered care in the intensive care unit must be maintained throughout conversations, assessments, and procedures involved in organ and tissue donation. While it is acknowledged that individual WLSM plans may be subject to variability in response to patient/family/SDM priorities, these principles of high quality care must be maintained.

Symptom management

1.1 Objective signs of pain, shortness of breath, agitation, and delirium should be used to guide symptomatic treatment. Neuromuscular blocking agents should be discontinued before withdrawal of life support to aid in symptom assessment.

1.2 Medications should be used both to treat current symptoms and in anticipation of symptoms that are likely to arise. The rationale for giving any comfort medication should be documented.

1.3 A specific titration schedule for opioid and sedative medications should be utilized and medications should be titrated to symptoms with no dose limit.

1.4 Pain and dyspnea should be treated with opioids before employing the use of sedatives for anxiety or agitation.

1.5 Medications to alleviate other symptoms such as excessive secretions, post-extubation stridor, and nausea should also be included in the care plan.

Discontinuation of treatment

2.1 Liberalized family visiting should be offered and where possible, a space for the family to gather privately should be arranged. The approach to monitoring should be reviewed with the family/SDM and the healthcare team. An unobtrusive signal should be displayed outside to alert members of the health care team that WLSM is occurring.

2.2 The pace and order of withdrawal should be individualized to the needs of the patient. However, consideration should be given to withdrawing vasopressors and inotropes first, followed by mechanical ventilation and the artificial airway.

2.3 All non-comfort focused medications and interventions should be discontinued including dialysis, transfusions, parenteral feeding, enteral tube feeding, intravenous fluids, blood work, and imaging studies.

2.4 Providing that the patient is comfortable, mechanical ventilation should be withdrawn as quickly as possible. In the absence of contraindications, the patient should be extubated to room air and non-invasive ventilation or supplemental oxygen should not be provided except for comfort.

2.5 Implantable cardiac defibrillators should be deactivated prior to WLSM, and consideration should be given to discontinuing or disabling transvenous or permanent pacemakers.

Family/substitute decision maker support

3.1 Family/SDM should be involved in shared-decision making.

3.2 Family/SDM should be invited to be present at the time of withdrawal and assist in patient care. This can include helping to provide comfort to the patient and assisting in symptom assessments.

3.3 Family/SDM should be offered spiritual and bereavement supports and efforts should be made to accommodate any religious or cultural rituals, including involvement of their own religious leaders.

3.4 Following the death of their loved one, family members should receive information on community bereavement resources along with a letter of condolence.

3.5 To facilitate excellent bereavement support, inter-professional team members should receive education on the grieving process and how to provide acute support.

3.6 Physicians should be available as needed for family/SDM and staff once life support has been withdrawn to answer questions and offer additional support.

Case audit and review

4.1 Debriefing with the inter-professional team should be considered after each WLSM case.

4.2 Case audits should be performed after each case to ensure that protocols were followed and to identify opportunities for improvement.

Donation after circulatory determination of death (cDCDD)

5.1 Patients should be referred to the provincial organ and tissue donation agency when there is a plan in place to WLSM.

5.2 The decision to proceed with WLSM should not be influenced by any member of the organ or tissue donation team. The patient and/or family/SDM should not be approached to discuss donation until after the decision to WLSM has been made by the patient or SDM and the treating team.

5.3 The principles of care during WLSM should be the same regardless of whether or not the patient is a candidate for organ donation, although the treatment plan may differ slightly in terms of symptom management and comfort medications. The orders for WLSM should be written by a member of the ICU team without input from the organ donation team.

5.4 Explicit consent should be obtained for the administration of any medications that are being prescribed to optimize the chances of organ donation, but are not normally part of WLSM, such as unfractionated heparin.

5.5 If the dying process is prolonged and the patient is no longer a candidate for organ donation, symptomatic management and family/SDM support will proceed as per the protocol outlined above. Tissue donation may still be appropriate and feasible in these situations.

For further details regarding organ and tissue donation after death by circulatory criteria, please consult your institutional organ and tissue donation policy.

eAppendix 9. Research Opportunities

Throughout the workshop participants identified research opportunities in relation to WLSM and deceased donation. The key areas for future research identified included:

- Support
    - WLSM decision support for families and for health care professionals
    - how to involve families in WLSM
    - support practices in low resource settings
- Debriefing
    - pre and post WLSM, best practices; who, when and how
- Bereavement
    - best practices
    - how to best support families within the ICU and longer-term post death
    - preparing health care professionals and care providers in provision of immediate and future support
- Perspectives
    - the provision and impact of spiritual, religious and cultural care
- WLSM Practices & Education
    - Health care providers expressed concerns regarding the perception of hastening death within the context of WLSM and donation whereas family member participants concerns focused more around the prolongation of death. A future research topic for consideration may be to better understand whether health care provider's assumptions about family's concerns align with what families are experiencing.

Additional areas for research in relation to WLSM and donation were identified including:

1. Are decisions to WLSM influenced by the potential to donate organs and/or tissues?
2. How have recently developed guidelines for WLSM influenced/impacted practice in Canadian intensive care units?
3. How can bereavement support be implemented into low resource critical care settings?
4. Are decision support/decision aids useful in facilitating discussions regarding goals of care as well as organ and tissue donation?
5. What are best-practices related to spiritual/religious/cultural care within the context of organ and/or tissue donation?
6. What are the experiences of family members regarding: i) family presence during WLSM; ii) debriefing following WLSM; iii) bereavement support post WLSM and organ and/or tissue donation?
7. What are the experiences of family members who i) stay at the bedside throughout the process of WLSM; ii) choose not to be present at the bedside throughout the process of WLSM?
8. What are experiences of ICU clinicians and family members regarding the use of continued monitoring during the WLSM?
9. What are the experiences of families who consent to donation after cardio-circulatory death but the patient does not expire within recommended guideline timeframes?

10. Has the prevalence of “consented, not recovered” of “all potential donors” remained consistent over time?
11. What factors constitute “non-recovery” and have these factors stayed consistent over time?
12. Are there instances whereby hastening death related to donation after cardio-circulatory death is ever permissible?
13. What are current trends/practices with respect to consent for a treatment plan in comparison with consent for individual components of a treatment plan?

Communication and collaboration are of high importance in relation to WLSM and donation research; both to be aware of research the community is undertaking and working collaboratively to build on that research and to ensure its dissemination.