Compassionate Deactivation of Mechanical Circulatory Support in Children

**BACKGROUND**

The process of compassionate deactivation of mechanical circulatory support (CDMCS) is extremely challenging for families and health care providers. CDMCS is considered to be both legal and ethical, and it is not considered a form of euthanasia because no new pathology is introduced, and the patient dies from the natural progression of his/her underlying disease.

**ACTION REVISED DATE:** 06/21/2019

**OBJECTIVES**

1. To provide a preparation guideline for CDMCS as a tool of integration, planning and preparation of patients, families, caregivers, and clinicians.
2. To utilize a standardized pathway that can be tailored to one’s individual needs and ensure a comfortable and dignified end-of-life experience for children on VAD support.
3. To provide information about CDMCS of the most common VADs used in children.

**PROTOCOL**

**1. Multi-disciplinary Team Communication and Preparedness Planning: Identify and contact key members listed below**

**1.1 Primary medical team: 1.2 Multi-disciplinary team:**

( ) Attending ICU physician ( ) Palliative Care consultant

( ) Primary cardiologist and/or On service cardiologist ( ) Social Worker (SW)

( ) Cardiothoracic surgeon ( ) Chaplain, as indicated

( ) VAD coordinator ( ) Ethics consult, as indicated

( ) Bedside nurse and Charge nurse ( ) Bereavement group, as indicated

( ) Respiratory Therapist (RT) and/or Perfusion Team ( ) Child Life Specialists (Patient/sibling support)

**1.3 Interdisciplinary care plan discussion and preparation for CDMCS**

( ) Assess provider comfort level with CDMCS plan and procedure (prepare for substitute staff if needed)

( ) Discuss and plan sequential steps for removal of other life sustaining therapies during CDMCS process

( ) Review each therapy patient may be receiving (Ex: Nutrition, Fluids, Dialysis, Inotropes, inhaled Nitric Oxide, Ventilation)

( ) Review deactivation of pacemaker or ICD (defibrillation and pacing functions) and timing according to steps below

**2. Family Meeting:**

**2.1 Family meeting preparation:**

( ) Identify and contact key stakeholders and leader

( ) Identify surrogate decision maker, if required

( ) Call Organ Procurement Organization or appropriate entity: determine candidacy for organ donation

**2.2 Meeting content:**

( ) Define agenda of the meeting and ask permission to discuss CDMCS process

( ) Review important goals for patient and family

( ) Outline CDMCS process, reiterating commitment to patient’s comfort, prioritizing patient’s and family’s values

( ) Outline comfort-directed therapies that will be continued or started, and therapies to be discontinued (ex.: dialysis, nutrition, ventilation, inotropes, laboratory draws, transfusions, pacemaker or ICD)

( ) Identify which family members plan to be present

( ) Plan religious rites and assistance, as indicated

( ) Explain unpredictability of timing of death (minutes, hours, days) and emphasize continuation of comfort care

( ) Plan care or steps after CDMCS: hospice if indicated, autopsy if indicated and funeral arrangements

( ) Offer resources for bereavement support: environment (respectful silence/ noise control, bereavement rituals with staff if available, family photos and keepsakes if available

( ) Clarify with family date and time for CDMCS

( ) Clarify date and time planned for CDMCS with multi-disciplinary team

**2.3 Documentation:**

( ) Document legal proxy decision-makers (i.e.: both mother/father, SW as needed)

( ) Document Advanced Directives of Care in accordance with local policies and laws (example below):

( ) Capacitated Patient: Attending must document conversation of patient or surrogate desire to have life-prolonging treatment withheld or withdrawn

( ) Incapacitated Patient: 2 Attending notes documenting terminal/end stage condition and no reasonable probability of recovering capacity or surrogate’s desire to have life-prolonging treatment withheld/withdrawn

( ) Document present members and content of family meeting

**3. Interdisciplinary end of life care at bedside for CDMCS:**

**3.1 Delineate team bedside roles and responsibilities:**

( ) Review and rehearse planned sequence for deactivation of VAD (specific to VAD type) and other life sustaining therapies discussed in family meeting, including alarm monitoring

( ) Identify member responsible for CDMCS

( ) Certify RT and equipment preparation

( ) Identify responsible bedside nurse and assistant: review medications for comfort at bedside and who will administer

**3.2 Orders**

( ) Review and discontinue orders that may cause discomfort and align with family wishes (Section 2.2: consider early discontinuation of inotropes to allow natural death to occur when device is turned off)

( ) Review, plan and continue Comfort Care orders:

( ) Ensure privacy (partitions, closed curtains) or consider moving patient to private room if possible

( ) Review PRN medications, doses and titration parameters

( ) Anticipate need of new drips, short acting opioids and benzodiazepines, anti-emetics, anti-pruritus

( ) Write and sign DNR order, if not already done

**4. Preparation of family at the bedside:**

**4.1 Certify available Multi-D Team, as indicated (SW, Chaplain, if desired)**

**4.2 Patient examination and family support:**

( ) Communicate to team important goals outlined by patient and/or family

( ) Exam patient and assess family’s perception of patient’s level of comfort

( ) Inform family what to expect (ex.: signs of dying and death)

( ) Discuss with family anticipated symptoms and pharmacological and non-pharmacological strategies for discomfort (anxiety, pain, secretions, noises, gasping, skin color changes)

( ) Clarify with patient or family desired attire for CDMCS (example: religious, ethnic or preferred attire)

( ) Inform family when preparation is completed.

The full checklist is available via this link, but also copied below for reference: <https://public.3.basecamp.com/p/ry93jf6WMCihXMVFWRt7FfWa>

**Device-Specific CDMCS** (links below to specific documents)

* Berlin Heart: <https://public.3.basecamp.com/p/6saWERpJXwcq1RKq3eBVHQ3b>
* HeartWare HVAD: <https://public.3.basecamp.com/p/vhrwhJFuosyERu11TLpKDLQt>
* HeartMate II and 3: <https://public.3.basecamp.com/p/GNyGYUukYH158E99BVq1Snmn>
* Pedimag & Centrimag: <https://public.3.basecamp.com/p/pfN7vE67mJfAV5BFtVymBpZU>

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**RESOURCES:**

1. Bruce RC, Allen NG, Fahy BN, et al. Challenges in Deactivating a Total Artificial Heart for a Patient With Capacity. CHEST 2014; 145 (3): 625-631
2. Schaefer KG, Griffin L, Smith C, et al. An Interdisciplinary Checklist for Left Ventricular Assist Device Deactivation, Jour of Pall Med, 2014, 17(1): 4-5
3. Hollander SA, Axelrod DM, Bernstein D, et al. Compassionate deactivation of ventricular assist devices in pediatric patients, J Heart Lung Transplant 2016;35:564–567.

***Disclaimer:*** *The ACTION network is focused on quality improvement efforts such as harmonizing best practice protocols, disseminating them among institutions, and helping centers to improve care practices at the local level. This protocol was developed as a consensus tool for pediatric VAD programs. The information in the protocols are based on center practices, individual opinions, experiences, and, where available, published literature. Centers may choose to adapt this protocol to include in their center-specific protocols with reference to ACTION with the understanding that these are meant as guidelines and not standard of care. (Revised 6/21/19)*