Catastrophic Brain Injury
Family Support Plan

1. **Give frequent clinical updates to family on patient's condition (clinical care team)**
2. **Healthcare team, especially bed-side nurse to advocate for family getting questions answered by physicians**
3. **Consult social services/chaplain/case manager/palliative care/child life/OPO for family support and reiteration of clinical condition.**
4. **Any member of the healthcare team calls a patient case conference to discuss catastrophic nature of injury and the necessity of using a common language with each other and the family**
5. **Invite family to participate in bedside care**
    - **Washing Face**
    - **Lotion to hands**
6. **Encourage personal items in room**
    - **Music**
    - **Pictures**
    - **Blanket**
7. **Ask family what is most important to them at this time**
    - **Spiritual care/Religious rituals**
    - **Family meetings with healthcare team**
    - **Access to the patient**
    - **Basic needs (work, child care, transportation)**
    - **Other urgent family needs**
8. **Show you care**
    - **Ask questions about the patient**
    - **Use the patient's name**
    - **Assess family's understanding**
9. **Discuss decision/change in patient's condition**

Supportive language

"He has suffered a severe injury to his brain, but we are doing everything possible to keep him comfortable."

"Our team of experts is offering him the highest level of care possible."

"Our commitment is to care for him as we would care for our own family."

"Nothing could prepare you for this. I am here to help you."

"We will take good care of him if you need to leave the hospital for awhile."

Change in Condition

Decision to Trach/Peg

Any member of healthcare team calls a patient care conference; consider including ethics first responder if needed

Update OPO on plan of care

Social Services begins rehab placement

Provide pt & family support/education

Update OPO if patient's condition deteriorates or family decides to remove ventilator

Decision to Discontinue Artificial Support

Any member of healthcare team calls a patient care conference; consider including ethics first responder if needed

Review Hospital policy on withholding/withdrawing life sustaining treatment

Consult ethics if needed for support

Update OPO when discussion begins about removing artificial support (pt may be a potential organ donor); repeat evaluation as needed

Deterioration to Brain Death

Update physician on patient's loss of brain stem reflexes as it occurs

Any member of healthcare team calls a patient care conference; discuss importance of using common and realistic language; invite support services and OPO staff so all members are receiving the same information

Obtain orders to maintain hemodynamic stability

Brain death examination; include family if desired

Supportive Language When Patient Progresses to Brain Death

"Despite our best efforts it appears that his condition has deteriorated. The physician is coming to the hospital to evaluate your loved one and update you."

"His neurological condition has changed. The physician will determine if there is any sign of life within his brain."

Donation is an end of life decision. It is important NOT to mention donation prior to brain death determination because:

- Pre-death mention of donation can lead to distrust.
- Surveys indicate families need time to process brain death diagnosis before they can move on to consider donation.
- Donation is not a "yes" or "no" question. A full discussion of end of life goals must occur.

What if the family brings up donation? Tell them, *"My commitment is to care for your loved one. I will contact an expert in that field and ask them to speak with you."*

Brain Death Exam

Supportive Language Enhances Family Understanding

100% of families report wanting to be offered the option of observing the brain death exam.*

1. Some families find it helpful to watch the tests that we do to determine if there is any life left in the brain. Would you like to be present for the examination?

2. I have checked to be sure that there is nothing that could interfere with his ability to respond (temp, labs, meds.)

3. Explain possible spinal reflexes: sometimes we see movement. Our goal is to differentiate between purposeful movement that originates in the brain, or reflexive movement that originates in the spinal cord. (Examples of reflexive movement: knee reflex when tapped with doctor's hammer or pulling away hand from a hot stove)

4. I am going to provide several types of stimulation to see if he responds.

    a. **Corneal**: *I am going to touch his eye with the tip of this q-tip. The normal response is a blink.*
    b. **Pupillary**: *I am going to shine a light in his eyes. The normal response is for the pupil to get smaller.*
    c. **Cough**: *I am going to suction him deeply. The normal response would be a cough.*
    d. **Gag**: *I am going to place this in the back of his throat. The normal response is to gag.*
    e. **Pain**: *I am going to provide a painful stimulation to see if I can elicit any response. Even people in a very deep coma would respond to this type of stimulation.*
    f. **Occulocephalic (Dolls Eyes)**: *I am going to turn his head. It is abnormal for his yes to turn with his head.*
    g. **Occulovesitublar (Cold Calorics)**: *I am going to flush his ears with cold water and observe to see if his eyes move at all. Again, even someone in a deep coma will have eye movements in response to this. No eye movement means that his brain is not working.*

5. *We are now going to proceed with the **apnea or breathing test**. We are going to turn off the ventilator and see if he initiates any breaths on his own. At the end of the test we will draw some blood and turn the ventilator back on. Would you like to stay in the room to observe this test?*

    a. If at any time his blood pressure or oxygenation drops significantly, we will stop the test and restart the ventilator.
    b. I am going to uncover his/her chest so we can closely watch to see if he/she takes any breaths.
    c. *It is important not to touch him or the bed as we will be watching closely for any breathing.*
    d. Do the apnea test.
    e. It will take several minutes to get the results back from this test. (Team member) is going to take you to the conference room. I will join you when I get the results.

*References:
Pearson, et al. Australia and New Zealand Intensive Care Society Statement and Guidelines on Brain Death and Model Policy on Organ Donation. *Anesthesia and Intensive Care*. 1995; 23: 104-108.
Franz, et al. Explaining brain death: a critical feature of the donation process. *J of Transplant coordination*. 1997; 7(1): 14-21.
Tawil I., Marinaro J., Brown L. Development and validation of a tool for assessing understanding of brain death. Progress in Transplantation. 2009; (3): 272-276

Donor Referral Line 1-800-DONORS-7

Critical Elements of Communicating Brain Death

1. Physician shares plan for BD exam with healthcare & donation team
   - Determine if family will be allowed to observe brain death exam

2. Physician offers family the opportunity to observe neurological exam
   - Physician performs appropriate brain death tests

3. Team member escorts family to a private room for physician led discussion of test results.
   - Everyone is introduced (team and family)

4. Physician reviews pt's clinical course in simple, easily understood terms
   - Initial injury, interventions, etiology of neurological decline
   - Use visual aids to enhance family understanding—CT, CBF study, models/drawing, etc

5. Physician reviews neurologic finding from brain death exam

6. Physician pronounces death
   - "Sadly, this means your loved one has died. His death certificate will show that he died at _____today."
   - Offer condolences

7. Take a breath…"allow silence to do the heavy lifting"
   - Physician bases next steps on family's response

Silence

"Please take some time to be with your loved one. When you are ready, our support team will help you with what comes next. I am going to step out of the room now unless you have questions about what I have just said. The nurses can find me if you have questions later."

Very Emotional/Anger

Listen & address concerns

"Please take some time to be with your loved one. When you are ready, our support team will help you with what comes next. I am going to step out of the room now unless you have questions about what I have just said. The nurses can find me if you have questions later."

Ready for Next Steps

"(OPO Coordinator name) is a member of our support team who specializes in supporting families at times like this. He/She and our team are here to help you. I am going to step out of the room now unless you have questions about what I have just said. The nurses can find me if you have questions later."

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Pearson, et al. Australia and New Zealand Intensive Care Society Statement and Guidelines on Brain Death and Model Policy on Organ Donation. *Anesthesia and Intensive Care*. 1995; 23: 104-108.

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