

# EDUCATION CORNER

## Communicating CBI / TBI to a Family

(CBI / TBI – Catastrophic / Traumatic Brain Injury)



Special thanks to Sarah Oland, LMSW, Director, Family Services, at Mid West Transplant Network for providing the content of this issue.

### References:

1. Siminoff L.A., Mercer M.B., Arnold R., (2003) Families' understanding of brain death. *Progress in Transplantation*, 13(3):218-224.

This inservice is also available on The Alliance blog:

<http://organdonationalalliance.org/education-corner-communicating-cbi/>

### Family Support:

1. Give frequent updates to family on patient's condition.
2. Advocate for family to get questions answered by physicians.
3. Consult social services / pastoral care / case manager for family support.
4. Provide and encourage conversations in the family's preferred language.
5. Invite family to participate in bedside care (e.g. washing face, applying lotion to hands, etc.).
6. Encourage personal items in the room (e.g. music, photos, blanket).
7. Ask family what is most important to them during this time:
  - Spiritual care / religious rituals
  - Family meetings with healthcare team
  - Access to the patient
  - Basic needs (work, child care, transportation)
  - Unmet urgent family healthcare needs
8. Offer compassion and personalized care:
  - Ask questions about the patient
  - Use the patient's name
  - Assess family's understanding of patient's condition
9. Consult the local Organ Procurement Organization if the patient is meeting clinical cues for a consult (e.g. ventilated and GCS of 5 or less, missing one or more brainstem reflexes and/or there is anticipated discussion of withdrawal of life-sustaining measures).

### Supportive Language:

*"He has suffered a severe injury to his brain, but we are doing everything possible to help him recover."*

*"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 a while."*

### When Anticipating Brain Death Testing:

*"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 and Brain Death:

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 indicates families need time to process brain death diagnosis before they can move on to consider donation. Research demonstrates families are more likely to donate if they understand the brain death diagnosis.<sup>1</sup>
- Donation is not simply 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."*