

## 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/chaplain/case manager for family support
4. Provide and encourage conversations in the family's preferred language
5. Invite family to participate in bedside care (i.e. washing face, lotion to hands)
6. Encourage personal items in room (i.e. 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)
  - Unmet urgent family healthcare needs
8. Show you care:
  - Ask questions about the patient
  - Use the patient's name
  - Assess family's understanding of patient's condition
9. Consult Iowa Donor Network if patient is on a ventilator, has a GCS of 5 or less, is missing 2 or more brain stem reflexes, there are plans to extubate for end-of-life care and/or the family mentions donation.

**IDN 24-Hour Referral Line: 800-831-4131**

## Supportive Language:

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

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

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

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

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

## When Anticipating Brain Death Testing:

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

*"His/her neurological condition has changed. The physician will determine if there is any sign of brain activity."*

## 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 indicate 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 a "yes" or "no" question. A full discussion of end of life goals must occur.

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