

The concept of brain death is difficult for many families to comprehend. However, it is generally helpful for families to understand that their loved one is dead before they have the discussion about donation. The following communication points may be useful in helping families to understand brain death.

- Provide frequent updates about the patient’s condition throughout the hospitalization. Consider using the sequenced statements provided in the “Communicating Brain Death Diagnosis to Families” information sheet to guide your explanations as the patient deteriorates to brain death.
- Ensure that all hospital staff give clear and consistent information to the family. It is important for all hospital staff to know what the family has been told about their loved one’s condition.
- Use visual aids (i.e. cerebral blood flow exam, cerebral angiogram or electroencephalogram) to describe the brain injury and death. Visual aids may help the family understand what they cannot see, since the patient’s body remains warm and normal in color while maintained on the ventilator.
- After declaration, refer to brain death as death. Explain to the family that the time of death is the time brain death was declared. This will be the time on the patient’s death certificate.
- Use the word death. Avoid commonly used euphemisms (pass away, gone, expired, etc.) in your conversation about the death.
- The patient is not in a coma. Refer to the ventilator and intravenous medications as ‘artificial or mechanical support.’ Be aware that talking to the patient during cares may mistakenly lead the family to believe their love one can still hear and comprehend.
- Encourage the family to ask questions and express their understanding of their loved one’s death. Allow moments of silence—try not to fill in gaps in conversation with meaningless words or explanations.
- When feasible, allow the family to observe parts of the neurological exams. Explain the medical equipment and its function in the care of their loved one.
- Every family, every loss, and every grief experience is unique. Work to adapt the content and style of your communication with each unique family.

Adapted from *Caring for Donor Families Before During and After* by R. Maloney and A. Wolfelt (2010)



Communicating Brain Death Diagnosis to Families



This form is to serve as a communication guide as family members process their loved one’s diagnosis. **DO NOT** mention donation. Communication with families is crucial when their loved one has sustained a devastating injury and/or their condition is deteriorating. Developing a family communication plan ensures families receive consistent and timely information. An early and unplanned mention of donation is often perceived as a conflict of interest as well as a display of unintended insensitivity to families. Consider the following suggestions when communicating brain death diagnosis to families.

Loss of 2 brain stem reflexes call Iowa Donor Network at 800-831-4131

1. Seriousness of Injury

“[Patient Name] has suffered severe damage to his/her brain. We are doing everything we can to help him/her recover.”

- Explain and reinforce injury/neurological involvement.
- Discuss plan of care with family.
- Check for understanding by the family and provide family support.
- Review and adjust communication plan to meet the needs of the family.

2. Grave Prognosis

“Despite everything that we have done, [Patient Name] is getting worse. He/she may not recover.”

- Explain and reinforce grave prognosis.
- Review treatment interventions and plan of care.
- Support family and try to assess their understanding.
- Review and adjust communication plan to meet the needs of the family.

Does family understand grave diagnosis?

Huddle with Iowa Donor Network to plan for donation conversation

3. Brain Death Testing

“As you know, [Patient Name] has suffered a devastating brain injury. It appears that his/her brain has stopped working and cannot possibly recover. We have begun tests to be certain about this.”

- Review treatment interventions to assure family everything possible was done.
- Differentiate between coma and brain death. Support family and try to assess their understanding.
- Explain the brain death testing process.
- Review and adjust communication plan.

4. Brain Death Discussion

“Testing is complete. [Patient Name] has lost all brain function. This is permanent. This means that he/she is medically and legally dead.”

- Explain results of brain death testing.
- Provide written information and/or visual aids.
- Support family and try to assess their understanding.
- Review and adjust communication plan to meet the needs of the family.

Does family understand probable brain death?

Does family understand brain death?

Huddle with Iowa Donor Network to enable and implement donation conversation