

## Keeping the Donation Conversation Open...

Donation is not a “yes” or “no” question. It’s a conversation. Families need to have all the information in order to make an informed decision.

**Below is some language that may be helpful in communicating with families:**

**A family in shock may not understand brain death or the need for comfort care in spite of their education level:**

- “It can be hard to understand because she looks like she is sleeping but her brain has lost all function.”
- “Sometimes even if it makes sense in our head it is hard to understand in our heart.”

**It is okay and even a good thing to give the family TIME to slow down:**

- “This is a lot to absorb.”
- “Talk to your friends and family about this.”
- “We have time.”
- “Take some time and get a cup of coffee.”
- “There are more things to talk about...why don’t you take a break and we will reconvene in an hour.”

**When a family decides to WLS immediately, explore keeping families’ options open:**

- Give them permission to slow the process down (see notes on giving them time above) and call the LCNW coordinator immediately
- It may become appropriate to say: “In my experience, families like yours sometimes have the option for organ donation. If [patient’s name] has donation options then someone will come speak to you before we take any more steps.”

**If the family says, “No we don’t want organ donation”:**

- When donation comes up too soon and a family reacts negatively, it is important to note they may be saying “no” to the death and not to donation. Some families may need more time to absorb the news that their loved one is not going to survive.
- “The decision to donate is a very important one; I would encourage you to be open to receiving more information about what it would mean for [patient’s name] to be an organ donor so ultimately you are able to make a fully informed decision.”
- “Now may not be the right time to decide whether or not donation is right for [patient’s name], why don’t you take some time to be with your family and sit with [patient’s name]. Someone can speak with you more about this later.”

**It is most important for the family to feel supported and have access to all possible donation information to make an informed decision:**

- Many families find comfort from donation either immediately or over time. It is common for donor families to express after the death how thankful they are for the opportunity to donate and how it has brought meaning to their loss
- Families ask questions about things they are worried about. It is ok to say, “I don’t know the answer to that but I do know the team will do everything they can to meet all of your needs and address all of your concerns.”
- The care team can offer the family confident reassurance and take every opportunity to move the process along so the family can make their decision in an informed and supported environment.