Family Conversation Resource Guide

The intent of this document is to provide guidance for LifeSource staff (at any level) in responding to questions in the midst of a referral or case involving challenges when working with families. This document is not intended to script responses. It gives the subtext, offers framework for the LS to consider, and provides guidance for messaging responses.

Definitions:
- **SPECIFIC CHALLENGES**: May occur at any time the time in a referral/case
- **SUBTEXT/CONSIDERATIONS**: The meaning which may be behind the spoken words. Considerations for framing the response.
- **MESSAGING**: Message suggestions that may help when responding to challenges.

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When feeling challenged, asking for more information is a good way to keep communication open – by using phrases such as: “would you say more about that?” you are able to be much more effective in exploring the opportunity of donation with every family.

Here is a great tool to keep in mind when faced with challenging circumstances – LAST.

- **Listen**
- **Acknowledge**
- **Support**
- **Thank**

- **Listen** to the message being given. Anger is OK, it helps us see that something needs attention; look for the subtext: Are they hungry, tired, embarrassed, fearful, hurt, ignored or misunderstood? Don’t retreat from anger, listen to what is being shared.
- **Acknowledge** the emotion: “I see you’re upset” or “I see …”, apologize if appropriate.
- **Support** a family and help them find what they need: “I may not (have the answer, be the ‘best’ person for this) but I can call…” “I’ll do my best to try to make this easier”.
- **Thank** the person for their input – it says “I’m no longer mad”. They may have been the upset person; and they may be feeling that you are also upset – this helps to defuse defensiveness.
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<td>I don’t want him to be all cut up</td>
<td>• Seek to understand their concerns. Family way out of “normal” experiences and trying to avoid how confusing it is.</td>
<td>• Help “normalize/stabilize” family’s circumstance, “Many families have shared that concern about disfigurement (this offers alternate and softer language to “cut-up”).</td>
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<td>• Family protecting loved one – acknowledge your respect for that:</td>
<td>• Acknowledge your respect for their desire to protect. “I respect your desire to protect Malik.”</td>
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<td>• Family may be protecting selves from vision of loved one all cut up.</td>
<td>• Seek to understand, “Would you mind saying more about that?”</td>
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<td>• May be worrying about funeral arrangements.</td>
<td>• It helps to soothe by noticing their circumstance: “Many families have shared that concern. I see you’re exhausted and this is hard.”</td>
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<td>“I can’t put them through anymore/can’t put me through anymore.”</td>
<td>• Variations on a theme of tiredness and inability to take in or process anymore.</td>
<td>• “I can see you’re exhausted. That’s so hard.”</td>
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<td>• When one has given up hope a hosp can feel like a pointless place to be-when exhausted it can feel like a prison.</td>
<td>• Offer guidance: “Something that helps some families is to take some time to leave the hospital and get what rest you can. Some people, knowing their family member has passed away, say a final goodbye and head home-others take some time off to rest and then return later.”</td>
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<td>• May soothe to have condition acknowledged and “see you’re tired” and helps family know you can be trusted to care for them and by extension, their loved one.</td>
<td>• I am so sorry for what you and your family are going through. Please know my intention is to be sure that you will feel good about all the decisions you’re making. I don’t want any of you to look back and wonder what you might have said if you’d had full information.</td>
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<td>“It’ll take HOW long?”</td>
<td>• See “can’t put loved one through anymore” and tiredness</td>
<td>• Acknowledge difficulty of what they are experiencing.</td>
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<td>• Acknowledge family’s suffering and exhaustion.</td>
<td>• Example: Don’t be afraid to repeat, “This must be so hard for you.”</td>
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<td>• Clarify family’s understanding of brain death.</td>
<td>“I know it seems like a very long time but making sure that we have all the right testing completed and all the right people ready, will help us be sure Tonya’s gifts will be put to the very best use.</td>
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<td>• You don’t need to stay for all that time. We’ll be with _____ and we’ll do everything we can to keep it as short as possible.</td>
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“I heard I heard about (_________) who was diagnosed brain dead and they’re fine. “

- May still be trying to hold on to hope
- May be suspicious of medical treatment—e.g., distrust of medical system.
- May simply be trying to understand all they’ve heard.

- You know, I’ve heard that kind of thing before and what I’ve come to know is that sometimes, in trying to describe a very bad head injury someone will use the term "brain dead". It’s a misuse. BD is a very specific diagnosis that means all, not just some of the person’s brain cells have died. It is descriptive of why they died—their brain failed. Just like cardiac death means someone died because their heart failed.”

“We never discussed it.”

- May feel uncertain of what to do in a new kind of situation. May be feeling abandoned (unconsciously) and hurt that loved one didn’t give them info they now need.
- Help them realize their experience is normal
- Provide guidance about how to go about making the decision

- “That’s true for a lot of people. We just don’t think about what we’d like after our death or we forget to let people know because we’re not with them when we think about it.” Reinforce role of support for the family.
- What other families in your situation have done is to ask what would _____ say about helping someone when there was no longer hope for themselves? What did she value? You can tell by what she did—did she like to help people?

It’s not listed on the driver’s license.

- They are searching for guidance about what the person wanted and wanting to support it.
- Provide leadership in how to think about information we have, not on what is not available because answer is blank.

- We know exactly what it means when someone marks Yes on their DL but we don’t have certainty about why they left it blank.
- They may have wanted their family to be able to decide. They may have been unsure.
- Since that decision does now fall to you the best way to make that decision is to really think about what _____ would say if he were here with us and he knew he could help someone? What did she value? You can tell by what she did—did she like to help people?
**“We’ve already made our decision and it’s No.”**

- Important here to try to learn what they based their decision on so they've made best informed decision possible.
- Need to assure them you will respect their decision and not try to change their minds.
- Listen for what information family most needs.
- My role is to support you and to be sure that you've made a well informed decision. I certainly respect whatever you decide. Very few people have accurate information about donation and I want to be sure that in the future you don’t get better information and regret your choice. Would you be willing to share a bit of how you made your decision?
- In my experience I’ve learned that some families are worried about funeral arrangements (disfigurement or timing), some are worried they’ll have to pay the expenses, some worry their loved one won’t be well treated or that they won’t have a choice about what they donate.
- Engage the family in conversation about their loved one:
  - “It would be an honor if you would share with me something about (patient’s name)? or I would be honored if you would share something about _________ with me.

**Timing of request—“I’m suffering and you want to intrude and ask me for something?”**

- Family is suffering and projecting feelings (fear, anger, grief) on LS or hospital staff.
- Offer family support and acknowledge pain.
- Avoid the tendency to apologize for donation. Give them more time—“I see it’s a bad time, a decision will need to be made pretty soon but not right this minute. I’ll step away for half an hour then we can all feel better about a short conversation for a really big decision.”
- Or
- “It sounds to me like you are unsure about organ donation and would like some time to process the information I’ve given you. I am going to step away to give you as much time as possible, without letting the window of donation opportunity close. I will come back and we will work through your concerns together.”
- Reinforce role of support for the family.
- Acknowledge the difficulty and pain of the situation.
- Express that our goal is to make the process as smooth as possible.
- Example: “My role is to do my best to support you.”
- Agree,“ I know it feels intrusive but because of all that’s needed for organ donation there’s no other time we can go through this.”
- If returning after giving time: “When I last saw you, you seemed unsure about donation for your daughter. I would like to reassure you that donation will save someone’s life. It is a fact. What concerns can we work through in order to provide your daughter the opportunity to be a hero?”
| Family disagreement with one another. | Quiet and non-judgmental listening is need to discern what folks are really disagreeing about.  
Is it donation or is it about who gets to make decisions at all. It may be about an unrelated or old relationship issue or misinformation  
It may help to simply act as a calm presence.  
Not our job to keep them from fighting, but it is our job to help them make a decision if possible | Ask what each is thinking, correct donation related misinformation.  
Remind them about their task – to make a decision on patient’s behalf by determining what she would do if she were here to tell us. |
|---|---|---|
| Religious objections: often expressed as “It’s against our religion.” | While we may know it’s inaccurate, the statement can mean a couple of things:  
Requires delicacy  
They may not really understand the stance taken by their faith community  
They may use it as an excuse to keep you from pressing them about a decision -it’s a strong value not to directly question someone’s religious views so can be effective as a way to avoid a fuller discussion. | We may be able to gently probe with, “Oh, I didn’t know, can you tell me more about that?” Helps keep the focus on our lack of knowledge and not theirs. Allows them room to explain or may open a door for us to say, “It had been my understanding that the saving of a life was of some higher value then preserving the whole body.”  
They may rethink or they may say—“Oh no, we have to bury them whole.”—where we can simply say “well thank you for helping me understand. It was my mistake.” |
| Dissatisfaction with attitude of/treatment by Hospital or OPO staff: | This can cause serious problems.  
Avoid agreeing with or commiserating with a family about how hospital staff has treated them. It is not our job to judge. | Neutral and quiet statements like.“I’m so sorry it’s been difficult.” “Sounds like you’ve really had a rough time of it.” Even murmuring can be helpful, “Mmmmm.” “Ohhh”  
Offer comfort as appropriate: “How can I help you?” “May I get you some coffee?” “May I see if I can arrange for a larger room for your family?” |
| Family—or medical staff ---have made own determination of patient’s eligibility | Important to listen closely so you find out this is what they are basing decision on. | The obvious counter to this is to give more information about screening and rule outs. |
## PHONE SUPPORT CHALLENGES

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<td>Dr. Smith tells you “the family has been through enough and I know that they will NOT be willing to talk with you.”</td>
<td>• Dr Smith is worried about burdening this family, he is feeling protective.</td>
<td>• Dr. Smith, I respect your concern for this family. I don’t want to assume anything or take an opportunity such as this away from the family . . .&lt;br&gt;• It may well be that they’ll refuse to talk with me or will pass on the chance for donation, but we can’t make that decision for them. They deserve the chance to choose what is right for their family and not have us withhold the choice from them by second guessing. They can’t make an informed decision without the information I can provide. I’d appreciate your support in helping this family be open to getting this information.</td>
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<td>Listen…..my family has been through enough, we have just lost our dad, my mom is not going to come to the telephone right now to discuss donation….</td>
<td>• Family is tired or overwhelmed.</td>
<td>• I am so sorry for what your family is going through, I can’t imagine; losing your father so suddenly. I appreciate your care in being an advocate for the rest of your family. Please know my intention is to be sure that your mom and the rest of your family will feel good about all the decisions you have to make. I don’t want any of you to look back and wonder what you might have decided.&lt;br&gt;• My role is to support you and to be sure that you’ve made a well informed decision. I’m hoping you’d be willing to share a bit about how you decided. Very few people have accurate information about donation and I want to be sure that in the future you don’t get better information and regret your choice.&lt;br&gt;• Not all families have this opportunity at the time of their loved ones death, your dad’s gifts of organ, tissue and eyes could go to help so many different people….for example, he could save another father from losing their leg to bone cancer or he could possibly allow another young man the ability to walk pain free after having needed back surgery or you may be familiar with diabetes, he may have the opportunity to provide a life saving cure to someone who suffers from diabetes by giving the gift of pancreas transplant etc…..&lt;br&gt;• I don’t want to assume anything or take an opportunity to save lives away from your family. If your father was here or a part of this conversation and he heard that he could save a life, (or many lives) what do you think that he might say?</td>
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We would only want Joe’s organs or tissues to go to individuals of Jewish faith (or any particular group of people) ....  

- Although, I don’t know and I won’t be able to guarantee who would receive Joe’s gifts—I do know that every individual waiting for the gift of transplant would hope that families such as yours would have the courage to take this opportunity. Such gifts impact the number of people waiting, never quite knowing who that individual could be or what their personal faith is. I would like to ask you a question, if Joe was able to hear this information, that through such gifts, over 60 lives could benefit from your families generosity in saying yes to donation, what do you think that he might say?

“I don’t think we’re interested. We’ve already made our decision and it’s No.”  

- “I know that your grief is incredibly strong and it is difficult to get past it. However, in the days ahead you will be able to take some solace in the fact that you and your mother saved the lives of others. You don’t want to look back and regret not making this decision.”

Hospital staff tells us family has already decided not to donate: (see possible response and then box below this one)  

- I certainly respect their decision, I’d like a chance to thank them and be sure they don’t have any wrong ideas about what it might mean to donate.

If family then agrees to come to the phone  

- I understand that you have expressed your thoughts about donation to the hospital staff. I want to thank you for considering giving the gift of life. Before I go I would like to explain to you what it really means to be an organ donor.”
Re-Opening the Donation Conversation

Every family has a right to have the information necessary for fully informed decision making, and it is our responsibility as an OPO to provide that information. An early “No” is often a reflection of the initial disbelief and denial commonly experienced at time of loss (Kubler-Ross, 1970). This should not be understood as a considered decision to decline donation.

When a family declines donation prior to a full discussion, we will ask them for time for information to be shared, including discussion of possible concerns and misunderstandings about the donation process, with the goal of ensuring an informed decision for every family. After these steps have been taken, when a family’s decision is still to decline donation, we believe that respectful acceptance of that decision is paramount, along with continued support of the family.

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| Family has told hospital staff they do not want to donate and they have not had a chance to speak with us or a CDR. | • Needless to say, this is not a time for persuasion and great care must be exercised to re-open discussion with the utmost respect.  
• We do not want to be pushy or disrespectful in any way.  
• Many grieving families, particularly members of non-dominant groups, take exception to any perception that we are using persuasion. For these families, and indeed for most families, explicit reference to the needs of recipients seems insensitive and indeed has not proven effective, unless this information is requested by family members  
• Say that there is a considerable amount of misinformation about donation and then go through the list: | • Always intro yourself “transparently” so family knows who you are.  
• If a family member reacts angrily or in an upset way to the introduction, take the time to respond to their concerns in an accepting way  
• Begin by acknowledging that the doctor or nurse has told you know that they have indicated that they may not be interested in the option of donation.  
• Strongly reassure the family that you will not in any way attempt to persuade them; that you are there to go over information so that they can be absolutely sure that they have made the right decision.  
• Some families have concerns that funeral arrangements would be affected.  
• Some families are concerned that there would be expenses to them  
• Some families worry that their loved one won’t be treated respectful.  
• or that the family won’t have a choice about which organs to donate  
• Families have shared concerns about how recipients are selected  
• Finally---Whatever your decision is going to be, I want to make sure that any questions you may have are answered … |

_Engage the family in conversation about their loved one:_

It would be an honor if you would share with me something about (patient’s name)? or I would be honored if you would share something about _________ with me.
**LifeSource Donation Designation Philosophy: Supporting Donor Designation**

Many individuals have made a lifetime decision to be an organ and tissue donor with the goal of helping others in need. LifeSource has the privilege of playing a role in fulfilling these wishes and to do so in a manner which honors the donor, provides comfort and support to their family and helps those waiting for a life-saving transplant. The Anatomical Gift Acts of 39 states and territories including MN, ND, SD, and WI state that a donation decision is a personal choice and a legally-binding decision which cannot be overturned by another individual. These laws were enacted by legislators who believe in the decision-making autonomy of citizens, commonly referred to as donor designation. Hospital staff and donation personnel are obligated under state law to honor and fulfill individuals’ donation wishes. More than half the citizens in the LifeSource service area have documented their wishes to be an organ and tissue donor. Honoring the documented wishes of the individual is an essential component of the LifeSource mission.

**Hospital Questions (questions raise opportunities to huddle)**

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| **We don’t always follow the living wills of patients, why is this any different?** | • Hospital staff member is concerned about inconsistency in practice.  
• Acknowledge difficulty when patient’s decision is different from family’s decision.  
• Importance of individual autonomy in making decision.  
• Desire to avoid conflict. | • Donation is a gift that a person has made during their lifetime. When someone checks the box, a promise is made that their gift will be honored. As stewards of donation we play an important role in fulfilling that promise.  
• LS can’t address living wills and why they are not always honored.  
• Speak to donation and the importance of upholding the promise that was made when someone registered as a donor.  
• When this individual made a decision to donate they were saying they want to help recipients. We can help fulfill that promise. |
| **What happens if our hospital doesn’t move forward with donation? What are the consequences?** | • Worried about risk and/or legal implications.  
• LifeSource will stand in partnership with donor hospital to fulfill donation and save lives.  
• Uniform Anatomical Gift Act (UAGA) law is clear that individual can make autonomous decision. | • We run the risk of damaging the public’s trust in honoring donation.  
• If donation not honored, sets a precedent for future cases at this hospital.  
• By not honoring the donor’s gift, we are not following state law. |
| You’re not going to make them are you? (us vs. them) Are you going to move forward? | • Support and sensitivity for family is priority for all of us.  
• Consistent and honest communication is utmost priority.  
• LifeSource is in partnership with the donor hospital. LifeSource and donor hospital leadership will work together.  
• Concern that the hospital (and the individual) will be pulled into the conflict. | • The decision was made by individual to donate following death. We have an obligation to respect the decision and honor his/her gift.  
• Most families support the decision, address their concerns and answer their questions.  
• Acknowledge difficulty in seeing family in pain with grief. LifeSource will provide the utmost compassion and respect for the donor and family.  
• Acknowledge the health care teams trusted relationship with the family. Ask them how they think we can best support the family together?  
• LifeSource will continue to provide support in the months and years to follow and will be available to clarify any questions or concerns for the family following the donation.  
• Acknowledge that even if donation mentioned to the family and previously declined, LifeSource will still connect with them. |
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| What if the family calls the media? | • Hospital staff is worried about the impact on the hospital/individuals.  
• LifeSource will be in partnership with donor hospital Public Relations to address media inquiries.  
• Most families do not call the media, even when they say they will. | • It is important that we do the right thing and that cannot change just because of media involvement.  
• LifeSource will work with your public relations department to address media inquiries.  
• LifeSource is committed to confidentiality about individual cases involving donation.  
• Ask if their Public Relations have been contacted. |
| What if the family calls their attorney? | • Fear of legal implications.  
• Hospital and LS will work together to support the family’s decision to seek information to answer their questions.  
• Uniform Anatomical Gift Act (UAGA) is clear in supporting individuals to make this gift. | • UAGA is clear that the decision to donate is similar to a gift from a will.  
• LifeSource may offer to have family's attorney talk with LS legal counsel.  
• Individual made the decision and was focused on helping others and it is our role to help fulfill that gift. |
| Aren’t you worried this will hurt donation in the long run? | • Concern for the consequences on both donation and the hospital.  
• Fulfilling donor designation builds trust in the system for individuals to know their decision will be followed-through. | Donation is a gift that a person has made during their lifetime. When someone checks the box, a promise is made that their gift will be honored. As stewards of donation we play an important role in fulfilling that promise. |
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| I didn’t realize this meant the family doesn’t have a choice (and I may take it off my license). | • The individual may be thinking about it for themselves, not the family.  
• The individual is thinking about themselves, and their family they are only seeing the conflict, not what led up to the conflict.  
• Support the family’s decision to seek information to answer their questions.  
• Uniform Anatomical Gift Act (UAGA) is clear and emphasizes the importance of individual autonomy in making decision.  
• Honoring the individual’s decision to donate when the family isn’t in full agreement may be hard to do, and it is the right thing to do.  
• Acknowledge the difficulty in seeing the family in pain with grief. Remind them that LifeSource will provide the utmost compassion and respect for the donor and their family.  
• Acknowledge the health care teams trusted relationship with the family.  
• Most families support the decision and may have questions or misperceptions to address. We can talk with the family about decisions they can make such as organs and tissues for research and funeral home. |
| How do we know he/she was giving informed consent? There isn’t much information provided at the DL Bureau. | • DD differs from the model of informed consent practiced on living patients (the method hospital staff is most familiar with).  
• Donor designation is a gift, not informed consent.  
• Decision is different than medical procedure when someone is living. The DD decision is similar to a gift from a will – just like an individual would make the gift of belongings in a will to be carried out following death.  
• The donation is a gift made during a lifetime, to be enacted after death. |
| What’s my role? What do we do next? Now what? | • Communication and partnership between LS and the donor hospital is of the utmost importance.  
• Lean on LS – we are here to support the donor, the family, and the hospital team.  
• Acknowledge the health care teams trusted relationship with the family. Ask them how they think we can best support the family together?  
• Acknowledge difficulty in seeing family in pain with grief. LifeSource will provide the utmost compassion and respect for the donor and family. |
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| Individuals don’t receive enough information about donation at the time they sign up for their driver’s license. How can this be considered consent? | Family looking for control.  
Support of family, sensitivity with family.  
Avoid power struggle.  
If appropriate let them know that information is available to everyone. | You may be right, she may not have known all that was involved.  
Even if it was impulse to check the box, impulse came from desire to help someone  
We will work to honor her desire that when she died she could help other people.  
Information is made available at the driver’s license bureau and via LifeSource websites. We cannot be sure if she received or read the information. |
| My loved one wouldn’t have wanted to remain on life-support.            | Family may be uncomfortable with ventilator.  
Family is worried their loved one is suffering. Assess family’s understanding of BD and provide clarification.  
Family wants to fulfill wish of their loved one (not to be on vent). A potential place for us to agree with family. | I understand, many of us don’t want to be hooked up to machines if we have no hope of recovery.  
Clarify understanding of BD, assure no pain or suffering. |
| He/She didn’t understand that donor designation meant organs and tissues. | May be family confusion or misperception.  
Find areas of agreement.  
Provide information about tissue and eye donation. | That may be true because tissue donation often doesn’t get the attention organ donation does.  
Tissue donation can touch lives of many, and is critical to those who receive it.  
We do know that she had a desire to help other people and tissue donation provides that opportunity. |
| I know my loved one... I know he/she wouldn’t have wanted this.         | Find agreement, seek understanding.  
Family may be saying they don’t want this. | Support the family, express sensitivity.  
Seek to clarify, ask them about their concerns. |
| Outside Influencer who is not engaged, the late family member arrival, or late objector. | Invite the new comer/ late arrival into the discussion – welcome their advocacy.  
Outside influencer is attempting to protect the family.  
Seek to understand their concerns. | Acknowledge their desire to advocate for the family.  
Ask them to share their concerns, address the concerns. |
| I want to be with him when he takes his last breath.                    | Family wants to be present at time of death, don’t want loved one to be alone. | Acknowledge understanding that death has occurred.  
Loved one’s last breath occurred prior to his/her declaration |
| What about desire to be with them when their heart stops? | • May also mean, “I need to know it’s over.”
• Need to clarify understanding of BD. | of death, assure no pain
• Example: “I know this is difficult however (name)’s presence is always with us and will forever be in our hearts.” |
| --- | --- | --- |
| If they knew what we were going to go through, he/she wouldn’t have checked the box. | • Family may be uncomfortable with mechanical support.
• Acknowledge family’s suffering and exhaustion.
• Clarify family’s understanding of brain death. | Acknowledge difficulty of what they are experiencing.
• Example: Don’t be afraid to repeat, “This must be so hard for you.” |
| We’ve lost so much already, how can you do this to us? | • Family is suffering and projecting feelings (fear, anger, grief) on LS or hospital staff.
• Offer family support and acknowledge pain.
• Avoid the tendency to apologize for donation. | Reinforce role of support for the family.
• Acknowledge the difficulty and pain of the situation.
• Express that our goal is to make the process as smooth as possible.
• Example: “My role is to do my best to support you.” |
| I’m calling the media! | • Avoid power struggle.
• Family can call media to seek their help. | Acknowledge difficulty of situation for the family.
• Example: “You certainly can call the media and seek their help.” |
| I’m going to call my lawyer! | • Family can call lawyer to seek their help – it may be helpful for them.
• Offer support and resource (connection of family and LS attorneys). | Acknowledge difficulty of situation for the family.
• Offer to support the family’s desire to seek their attorney’s help. |
| What if I disagree with donation? (Are you telling me I don’t have any say in this?) | • Family feels they have no choice and all decision making has been taken away (loss of control).
• Individual made decision and family doesn’t have to make decision. | Seek clarification about the family’s specific concerns.
• Restore what control the family does have (research, funeral home, etc).
• Reiterate LifeSource’s efforts to support the family in fulfilling their loved-one’s desire to help someone else.
• Example: “My hope is that you would feel good about supporting (name)’s decision.” |