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Learning Objectives

This training manual provides learners with information to develop skills for discussing organ, tissue and eye donation opportunities with families. Upon review of this information Certified Designated Requestors (CDRs) should be able to:

- View themselves as donation specialists and advocates.
- Describe the importance of the role of CDR as well as their hospitals process for connecting CDRs to LifeSource, and patient families.
- Understand the philosophical framework for obtaining authorization for organ, tissue, and eye donation.
- Apply the elements of a family donation discussion to scenario-based skills practice and family donation discussions.

CDR Position Description

A Certified Designated Requestor (CDR) embraces the practice and philosophy of compassionate care for families needing to make donation related decisions. They recognize the value donation brings to the families as well as the wider community their healthcare organization serves. In collaboration with LifeSource they strive to maximize every donation opportunity by verifying the presence of donor designation, learning all they can about family needs and dynamics, and planning a donation conversation. They are knowledgeable about the donation process and provide decision-making guidance for families making donation related decisions. A CDR provides emotional support to families before, during, and after the donation discussion.

CDR Commitment

Your participation in the CDR training and completion of the required paperwork expresses your commitment to the Certified Designated Requestor (CDR) program.

After review of this training manual you will be asked to acknowledge that you have read and reviewed this document and will incorporate the information into your donation discussions.

Coverage and Availability

Your hospital may choose to utilize CDRs 24 hours a day, 7 days a week for all organ, tissue and eye donation opportunities; or CDRs may approach only if a donation agency Donation Coordinator is unavailable; or there may be an alternate plan in place. Please refer to your hospital-specific plan or consult with your hospital liaison to determine CDR coverage at your hospital.
Confidentiality

Organ and tissue donation is confidential. Hospital personnel and LifeSource staff must keep all information confidential concerning both donors and transplant recipients. This includes laboratory, medical, social, and other related information. Communications about the donation remain confidential to the public as well as to hospital employees who are not directly involved in the donation coordination. Decisions a family makes after their loved one has died are also confidential.

Mindset: Communicating by Design

A Certified Designated Requestor is a leader of high stakes conversations, a donation expert, and a patient and family advocate. Conversations about organ, tissue, and eye donation come at a critical time for families and has long term consequences for them as well as potential recipients.

Families deserve us serving them with our best abilities. Before we have any donation conversations a good place to start is by understanding that along with LifeSource you are partnering with family to help them make their best decisions in their worst times.

Taking the time to identify your intentions as a partner is useful and we suggest adopting the following Partnership Intentions and using them to help guide your interactions. When each intention is met, excellent partnerships occur.

PARTNERSHIP INTENTIONS

1. I get my needs met,
2. The family or the stakeholder gets their needs met,
3. A long-term relationship is fostered,
4. Any previous “messes” are (appropriately) addressed and cleaned up, and
5. The family or stakeholder is inspired (i.e., left in the presence of a vision).

EffectiveArts  www.effectivearts.com
Fast Facts about Donation

Thousands of men, women, and children in the United States are waiting for organ transplants that could save their lives. Each year, approximately one-third of those people receive life-saving transplants and a hope for a renewed life because of the generosity of individuals who at a time of personal grief think of others in need. Despite this generosity, the need continues to grow.

The Waiting List

<table>
<thead>
<tr>
<th>Organ</th>
<th>National</th>
<th>Regional</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney</td>
<td>95,104</td>
<td>2,650</td>
</tr>
<tr>
<td>Pancreas</td>
<td>886</td>
<td>143</td>
</tr>
<tr>
<td>Kidney-Pancreas</td>
<td>1,641</td>
<td>207</td>
</tr>
<tr>
<td>Liver</td>
<td>13,961</td>
<td>507</td>
</tr>
<tr>
<td>Heart</td>
<td>3,992</td>
<td>183</td>
</tr>
<tr>
<td>Heart-Lung</td>
<td>49</td>
<td>10</td>
</tr>
<tr>
<td>Lung</td>
<td>1,445</td>
<td>71</td>
</tr>
<tr>
<td>Intestine</td>
<td>248</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total Waiting</strong></td>
<td><strong>114,694</strong></td>
<td><strong>3,475</strong></td>
</tr>
</tbody>
</table>

Each day, 22 people die while waiting for a transplant. A new name is added to the transplant waiting list every 10 minutes.

Register to be an organ, eye and tissue donor at www.life-source.org.

Donor Designation

<table>
<thead>
<tr>
<th>Region</th>
<th>% of Adults Registered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minnesota</td>
<td>62</td>
</tr>
<tr>
<td>North Dakota</td>
<td>65</td>
</tr>
<tr>
<td>South Dakota</td>
<td>64</td>
</tr>
<tr>
<td><strong>Region Total (January 2017)</strong></td>
<td><strong>64</strong></td>
</tr>
<tr>
<td>National Total (2017)</td>
<td>54</td>
</tr>
</tbody>
</table>

Donation to Transplant

How quickly must organs and tissues be transplanted after recovery surgery? Transplant must occur within...

<table>
<thead>
<tr>
<th>Organ</th>
<th>Time Frame</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart</td>
<td>6 Hours</td>
</tr>
<tr>
<td>Lung</td>
<td>18 Hours</td>
</tr>
<tr>
<td>Kidney</td>
<td>14 Days</td>
</tr>
<tr>
<td>Pancreas</td>
<td>14 Days</td>
</tr>
<tr>
<td>Liver</td>
<td>14 Days</td>
</tr>
<tr>
<td>Heart-Lung</td>
<td>14 Days</td>
</tr>
<tr>
<td>Intestine</td>
<td>14 Days</td>
</tr>
<tr>
<td>Corneas</td>
<td>5 Years</td>
</tr>
<tr>
<td>Tissue grafts (bone, skin, veins, etc.)</td>
<td>5 Years</td>
</tr>
</tbody>
</table>

Gifts Given & Received

2017 Statistics

<table>
<thead>
<tr>
<th>Type</th>
<th>National</th>
<th>Regional</th>
</tr>
</thead>
<tbody>
<tr>
<td># of deceased organ donors</td>
<td>10,281</td>
<td>184</td>
</tr>
<tr>
<td># of living organ donors</td>
<td>5,975</td>
<td>218</td>
</tr>
<tr>
<td># of tissue donors</td>
<td>30,000</td>
<td>568</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Type</th>
<th>National</th>
<th>Regional</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney</td>
<td>20,638</td>
<td>626</td>
</tr>
<tr>
<td>Pancreas</td>
<td>1,002</td>
<td>43</td>
</tr>
<tr>
<td>Liver</td>
<td>8,082</td>
<td>212</td>
</tr>
<tr>
<td>Heart</td>
<td>3,273</td>
<td>77</td>
</tr>
<tr>
<td>Lung</td>
<td>2,478</td>
<td>67</td>
</tr>
<tr>
<td>Intestine</td>
<td>109</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total # of Organs Transplanted</strong></td>
<td><strong>35,582</strong></td>
<td><strong>997</strong></td>
</tr>
</tbody>
</table>

Patient Success Rates

One Year Post Transplant

<table>
<thead>
<tr>
<th>Organ</th>
<th>Success Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney</td>
<td>96%</td>
</tr>
<tr>
<td>Pancreas</td>
<td>95%</td>
</tr>
<tr>
<td>Liver</td>
<td>86%</td>
</tr>
<tr>
<td>Heart</td>
<td>87%</td>
</tr>
<tr>
<td>Lung</td>
<td>83%</td>
</tr>
<tr>
<td>Heart-Lung</td>
<td>65%</td>
</tr>
</tbody>
</table>

Regional data includes Minnesota, North Dakota, and South Dakota.
Data source: http://optn.transplant.hrsa.gov and AATB
Donation Opportunities
The Benefits of Organ Donation

One organ donor can potentially help up to eight people. Organ transplants are the treatment of choice for people who are suffering from end-stage organ failure.

<table>
<thead>
<tr>
<th>Organ</th>
<th>Benefits</th>
<th>Diseases of those awaiting Transplant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart</td>
<td>Life-saving replacement of a poorly functioning heart for those with end-stage heart disease.</td>
<td>Cardiomyopathy, Congenital defects</td>
</tr>
<tr>
<td>Lung(s)</td>
<td>Life-saving lung replacement for patients with end-stage lung disease.</td>
<td>Cystic fibrosis, Emphysema, Pulmonary hypertension</td>
</tr>
<tr>
<td>Liver</td>
<td>Life-saving replacement of diseased liver for those with end-stage liver disease.</td>
<td>Biliary atresia, Primary cholecystitis, Hepatitis</td>
</tr>
<tr>
<td>Pancreas/Islet Cells</td>
<td>Life-saving/life-enhancing organ replacement for patients with diseased pancreas. Eliminates the need for insulin injections.</td>
<td>Diabetes</td>
</tr>
<tr>
<td>Kidney(s)</td>
<td>Life-saving/life-enhancing organ replacement for patients with kidney failure.</td>
<td>Kidney disease, Diabetes, High Blood Pressure</td>
</tr>
<tr>
<td>Small Intestine</td>
<td>Life-saving/life-enhancing organ replacement for patients with diseased small intestine. Restores the nutritional balance of the body.</td>
<td>Short bowel syndrome, Digestive disorders</td>
</tr>
</tbody>
</table>

Each year, approximately one-third of people waiting receive life-saving transplants and a hope for a renewed life because of the generosity of individuals who at a time of personal grief think of others in need. Despite this generosity, the need continues to grow.
The Benefits of Tissue & Eye Donation

One tissue donor can potentially help up to 60 people. Most tissue transplants take place at community hospitals during surgeries that repair injuries sustained by trauma or disease.

<table>
<thead>
<tr>
<th>Tissue</th>
<th>Benefits</th>
<th>Diseases of those awaiting Transplant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bone</td>
<td>Replace lost or damaged bone for support and reconstruction</td>
<td>Trauma</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cancer</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Spinal fusion</td>
</tr>
<tr>
<td>Connective</td>
<td>Knee tendon &amp; ligament repair</td>
<td>ACL repair</td>
</tr>
<tr>
<td>Tissue</td>
<td>Uterine &amp; bladder slings</td>
<td>Bladder or uterine prolapse</td>
</tr>
<tr>
<td>Skin</td>
<td>Temporary covering for burns and reconstructive surgical procedures</td>
<td>Burn victims</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Reconstructive procedures</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Breast cancer</td>
</tr>
<tr>
<td>Vessels</td>
<td>Patients undergoing by pass surgeries and patients needing dialysis shunts</td>
<td>Coronary artery disease</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Kidney disease</td>
</tr>
<tr>
<td>Heart Valves</td>
<td>Heart valve replacement, especially for children &amp; women of childbearing age; recipients are not required to take anti-coagulants</td>
<td>Whole heart removed. Aortic and pulmonic valves dissected for transplant</td>
</tr>
<tr>
<td>Eyes/Corneas</td>
<td>Replace disease or damaged corneas, reconstructive surgeries post trauma</td>
<td>Corneal abrasion or scratch</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Congenital and corneal disease</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Puncture wounds</td>
</tr>
</tbody>
</table>

Approximately one million tissue transplants occur in the United States each year. More than 50,000 corneal transplants occur in the Unites States each year.
Gifts in specific circumstances:

**Non-vented Patient Death**

Tissues /Eyes
- Corneas
- Heart Valves
- Veins/Arteries
- Bone
- Connective Tissue
- Skin

**Vented Patient Death**

(Brain Death) (Circulatory Death)

### Organs

<table>
<thead>
<tr>
<th>Organ</th>
<th>Tissue/Eyes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart</td>
<td>Corneas</td>
</tr>
<tr>
<td>Lungs</td>
<td>Heart Valves</td>
</tr>
<tr>
<td>Pancreas</td>
<td>Veins/Arteries</td>
</tr>
<tr>
<td>Intestine</td>
<td>Bone</td>
</tr>
<tr>
<td>Kidneys</td>
<td>Connective Tissue</td>
</tr>
<tr>
<td>Liver</td>
<td>Skin</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Organ</th>
<th>Tissue/Eyes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lungs</td>
<td>Corneas</td>
</tr>
<tr>
<td>Pancreas</td>
<td>Heart Valves</td>
</tr>
<tr>
<td>Kidneys</td>
<td>Veins/Arteries</td>
</tr>
<tr>
<td>Liver</td>
<td>Bone</td>
</tr>
<tr>
<td></td>
<td>Connective Tissue</td>
</tr>
<tr>
<td></td>
<td>Skin</td>
</tr>
</tbody>
</table>
In addition to the benefits that transplant recipients receive, the bereaved family is presented with opportunities that, in time, may help them cope with the sudden and tragic loss of someone special. One of the benefits for families choosing to donate organs and tissues includes knowing that their loved one’s gift has provided an extension or improvement of the quality of life for another person.

The process begins with a patient who meet triggers for referral to LifeSource. All patient deaths (imminent and circulatory) must be referred to the donation agencies. Call within an hour of when a patient meets one of the following triggers:

1) A family mentions donation or has questions (or you have questions),
2) Ventilated patient and
   - Neurological injury
   - GCS \(< 5 \) or meets two or more of the following neuro indicators (no pain, no triggering the vent, no pupil response, no corneal reflex, no cough, no gag, no doll’s eyes, no response to cold caloric)
3) After initial referral, if a decision to withdraw support, call prior to extubation, or discontinuing life-sustaining therapies
4) Cardiac death

For non-vented patients who have cardiac death (tissue and eye):
- Staff should call LifeSource to report death and determine tissue and eye opportunities and donor designation status. A CDR should collaborate with LifeSource to develop a plan to talk with family.
  - Once the family conversation is complete let LifeSource know the outcome and collaborate for completing paperwork and recovery plan if family wants to support donation.

For vented patients (organ, tissue, and eye):
- Hospital and LifeSource will follow patients progress. If patient appears brain dead or family decides to withdraw support of life sustaining measures, call LifeSource PRIOR to extubation and collaborate with LifeSource Coordinator to determine which organ, tissue and eye opportunities exist and the patient’s donor designation status. CDR should collaborate with LifeSource to develop plan to talk with family.
  - Once family conversation is complete let LifeSource know the outcome and collaborate for completing paperwork and plan for LifeSource team to come onsite if family wants to support donation. CDRs continue to support family.
  - Close collaboration with LifeSource is essential for great family care!!
Collaboration and Huddles

To ensure a smooth process for all involved, a CDR should expect to “huddle” with LifeSource (typically via phone) from the time they first learn about a potential donation conversation, until a family donation conversation is complete and reported back. Huddles may be initiated by anyone. A huddle may take various forms, e.g., in person or via phone, but it is always a forum to exchange information. As a CDR, you may be asked to help facilitate a team huddle.

It is critical that members of the hospital care team are “in the loop” about how donation fits into family needs and patient care. Team members may include the CDR, bedside nurse, attending physician, fellow, resident, hospitalist, chaplain and/or social worker.

Topics of discussion during huddles may include:
- donation opportunities
- brain death determination
- appropriate timing of discussions
- family dynamics, legal next of kin (LNOK)
- donor designation status
- plans for further evaluation

If family is supportive of donation, additional huddles will take place to communicate plans for completing paperwork and for the LifeSource team to come onsite. Prior to the team arrival, a CDR should anticipate providing or arranging for family to be supported.

Before any family conversation be sure to huddle with LifeSource so they can let you know which opportunities exist and the patient’s donor designation status. This will equip you with the very basics of what you need when speaking with a family.

Important Reminder: LifeSource has access to the donor registries in your state as well as across the country and will provide you with the Donor Designation status of the patient. Do NOT attempt to get this information on your own (e.g., do not ask family, do not look for patient’s driver’s license).
- A family frequently does not know most current donor designation status.
- A physical driver’s license is often inaccessible and may be out of date.

Seeking the information on your own frequently causes confusion and uncertainty for families. It may affect the trust needed for effective support and can be difficult to sort out if the most recent information is in any way mismatched to what you learn.
What are we talking about in our donation conversations?

The short answer is we are speaking with families to learn how, on their loved one’s behalf, they want to support O/T/E donation. We are to help guide them as they make important donation related decisions.

Who Decides?

The controlling law for answering the question of, “Who decides?”, is the Uniform Anatomical Gift Act (UAGA). A primary premise of the UAGA is that an individual is the best judge of their own wishes.

It says that if someone decides that upon their death they want to make a gift of their O/T/Es, and they put that in writing, their decision controls. It explicitly states that no one, even family, may overturn that decision.

1) Patient: Authorization by Donor Designation (DD)

When we say, someone is “Donor Designated” we mean they decided to be a donor and documented it. It may have been documented on:

- A driver’s license
- A state-issued identification card
- Registration on state donor registry
- A will or an advanced directive
- A donor card or other writing, signed by the individual, intended to make an anatomical gift.

The UAGA goes on to say that if they do not put their intent regarding an anatomical gift in writing, the second- best decision makers are people the statute defines as Legal Next of Kin (LNOK).

2) Legal Next of Kin: Authorization by Legal Next-of-Kin

When donor designation is not present the decision of whether to make a gift falls to the legal next-of-kin. The Anatomical Gift Act designates the priority order of the legal next-of-kin.

<table>
<thead>
<tr>
<th>Legal Next of Kin in Descending Order</th>
<th>Minnesota</th>
<th>North Dakota and South Dakota</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Agent;</td>
<td>(1) Agent;</td>
<td></td>
</tr>
<tr>
<td>(2) Spouse;</td>
<td>(2) Spouse;</td>
<td></td>
</tr>
</tbody>
</table>
When the LNOK needs to decide the initial gift question we must talk with the highest ranked class of kin. For example, if the patient has a document appointing a healthcare agent, and the agent is reasonably available, then they are the one to make the decision. If there is not a documented agent and the patient is married, then the decision falls to the spouse. If they are unmarried it moves to adult child and so on.

Importantly, even if the hospital is relying on someone to make decisions for a patient, OTE donation may require a totally different individual or group of individuals.

We are not allowed to skip a class of kin unless someone in a higher ranked class tells us to skip them OR no one in a higher rank is ‘reasonably available’. Attempts to contact highest order LNOK should include asking family, hospital staff, or community partners (e.g. Police) for contact information and making at minimum two attempts to connect with the LNOK. During attempts a call back number should be provided if it is clear you have reached the proper number.

**** It is not necessary to memorize this list—LifeSource will always guide you in determining who is LNOK, but it is important to understand how the list works. LifeSource will help CDR determine LNOK

**How death may occur:**

**Brain death** is the irreversible cessation of all brain activity, including the brain and brain stem. The brain dies from lack of blood/oxygenation.

**Circulatory death** is the irreversible cessation of all circulatory and respiratory function. Circulation and oxygenation stops.
**What needs to be decided?**

It depends: the following chart gives some guidance. A critical component of any conversation is knowing if the patient has already made the decision to give a gift (Donor Designation) or if that decision will fall to the family. **If they are donor designated, then the decision that falls to the family is whether they are willing to accommodate what is needed for donation to move forward.**

For tissue/eye exclusive that means completing a medical-social history and for organ – where the patient has not yet died, will they adjust end of life plans to accommodate timing and testing needs.

Notably: if a patient is brain dead, then there are no decisions the family NEEDS to make. Donation will move forward regardless of family support. That said, we ALWAYS seek family support of their loved one’s decisions and will continue to inform and support them throughout the process.
When do we talk with families?

1) If they mention or inquire about donation, or
2) If patient dies (either Brain death or Cardiac death has occurred), or
3) If family of vented patient decides to withdraw life sustaining measures

Of note***** More and more families are bringing up donation during different phases of their loved one’s hospital stay. There are many potential circumstances for a family to mention donation. The suggested language here can be modified for the most common family mention scenarios. Even as CDRs, these responses work well when the family mentions donation prior to referral calls or if it comes up unexpectedly.

Three components of an effective response for families when they mention donation:

- **Acknowledge** the donation comments and assess of time is right for immediate conversation
- **Connect** with family as CDR and if timing is right connect with LifeSource to plan donation conversation.
- **Stay and Support** the family and patient

Practice saying these responses with a colleague. Imagine that the family mentions donation before or after the donation referral call has been made, but prior to the grave prognosis.

**Acknowledge:** “Our hospital supports donation and making sure all of your questions are answered.”

**Connect:** “We work with an organization called LifeSource, the experts in donation. I’ll give them a call so I can connect with them and see if there is anything we should particularly pay attention to.”

**Stay and Support:** *If the time is not yet right for conversation, “I have made a note of your question about donation and when we’re at the right time for that conversation we can cover it. Until then know I won’t forget and let’s focus on the other important things you need to be doing.”*

**The Nuts and Bolts**

On a high level, all donation is the same. Someone dies in a circumstance that allows donation, they are evaluated to determine which gifts are possible, someone authorizes the gift(s) which are then offered and accepted. Surgery occurs and gifts are sent to accepting parties.

At the next level, more specifics emerge.
**Tissue/Eye** may occur if patient is already deceased and is either ventilated or not. If not, and the time of their death is known and not too far in the past (less than 24 hours) then we move to further evaluation of their health. If there are no social or medical history rule-outs, then patient (DD) or family decide to authorize the gift. LifeSource will either come on site or transport the donor to LifeSource for tissue and eye recovery. Surgery occurs and the gifts are then sent for processing and on to recipients.

**Organ donation** may occur if patient is ventilated and supported for hemodynamic stability. Health is evaluated and if no rule outs patient (DD) or family decide to authorize gift. If authorized LifeSource will come onsite.

**If vented patient is Brain dead,** then LifeSource will come to hospital and clinically manage patient and do deeper evaluation of specific organs. LifeSource will arrange to offer gifts to transplant physicians, per UNOS policy, and when all offers are accepted will arrange OR timing. Along with our hospital partners we will continue to support and educate family. Once gifts offered and accepted and OR finalized we will take donor to surgery and send gifts to recipients.

Because the patient has died, and adequate oxygenation and blood pressure must be maintained, the ventilation of the patient does not stop until midway into surgery. This decreases warm ischemic damage to the organs—thus ensuring better outcomes for recipients. The family will say good-byes prior to the transport to the OR and will not see their loved one without the tubes associated with mechanical support.

**If vented patient is not yet deceased** and they or their family have authorized donation, LifeSource will come to hospital and assist with clinical management and deeper evaluation of potential gifts. This is DCD. LifeSource may make suggestion for patient clinical course but does not takeover clinical management—live patient continue to be managed by the hospital.

More details are written in the next sections.
Donation after Brain Death

Helping Families Understand Brain Death

The concept of brain death is difficult for most families to comprehend. However, it is important for families to understand that their loved one has died before they are offered the opportunity to make decisions about donation. It is important that the CDR print and review their hospital’s policies and procedures surrounding Brain death. It’s equally important they share the information with other members of the care team.

The following communication points may be useful in helping families understand brain death.

- Provide frequent updates about the patient’s condition throughout the hospitalization. Consider using the following sequenced statements to guide your explanations as the patient deteriorates to brain death.

- Ensure that all hospital staff gives 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.

- After declaration, refer to brain death as death. Tell the family the time of death. The patient is not in a coma. Refer to the ventilator and intravenous medications as “artificial support.” Avoid commonly used euphemisms (passed away, gone, expired) in your conversation about the death.

- Encourage the family to ask questions and give 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.

Some families may need a visual aid to fully understand the concept of brain death.

![Blood Flow](image1.jpg) ![No Blood Flow](image2.jpg)
Donation after Circulatory Death (DCD)

In some instances, a person may donate organs after cessation of circulatory and respiratory function has occurred. For donation after circulatory death (DCD) the following circumstances must exist:

- Life-sustaining medical treatment/ventilator support present,
- Planned withdrawal of life-sustaining medical treatment/ventilator support,
- Primary healthcare team and LifeSource evaluate potential gifts considering patient condition and circumstances.

In this situation, organ and tissue recovery occur only after support is withdrawn and circulatory death is pronounced. It is important that a CDR know the policies their hospital has adopted - it is always a good idea to print and review them. Also, important to share it with other care team members.

The donation process, especially organ donation, is complicated. It is important that CDRs become familiar with the donation process in general as well as their hospital’s specific policies and procedures. LifeSource is expert at navigating donation and is adept at following the varying hospital policies in all 280 hospitals where we partner. You can rely on us to partner and guide you but it is your responsibility to educate yourself on how things work at your hospital.

Deceased donor donation is the only kind a CDR or LifeSource will be speaking about with patient families. It may seem obvious that donation occurs only after death but sometimes requestor’s get confused when they begin a discussion about Donation after Circulatory Death (DCD) because the location of where a patient dies is unfamiliar and the unfamiliarity of caring for a patient in a different area can be disconcerting.

In DCD, the terminal extubation of a patient occurs in a surgical suite rather than in the Emergency Room or ICU. This sometimes leads people to think that the surgery will begin before the patient reaches PEA or Asystole and that is simply not accurate. Deceased donor surgery begins only AFTER death has occurred.

Surgical staff may not be as familiar with managing comfort care medications as an ICU nurse and may worry that we are bringing a patient to their OR to hasten death for a patient and recover their organs. They may need education and reassurance about the policies and procedures regarding comfort care of all patients at your hospital and they need to know you are following the identical processes for the potential organ donor. The ICU nurse will be administering the identical medications in the same amounts as would be used in any terminal extubation—the goals of care absolutely remains the same --- the comfort of the patient and care for their family.
The process of DCD donation is different than when a patient has already died (Brain death) and remains on ventilator support until mid-surgery. However, in many ways DCD donor death is almost entirely the same as a circumstance where a family has accepted that continued medical care is futile and seeks to move to comfort cares.

With DCD, the family made the decision to discontinue life sustaining measures (typically prior to donation conversation) and LifeSource and the hospital work with the family to determine timing and place where extubation to occur. We accompany patient and family to the OR, and when patient is extubated we remain in the OR until death is declared. Patient is given identical comfort medications as non-donors extubated in the ICU and is attended to by the ICU bedside RN.

If the patient dies within prescribed time to allow donation, we help family leave the OR and surgery will begin shortly after death pronouncement. If patient does not die within timing parameters, then we accompany patient and their family to prearranged hospital room to continue death vigil. The time allowed to progress to death is short as extended ischemic damage results in damage that destroys transplant viability.

**Tissue and Eye Exclusive**

Tissue and eye donation may occur even when organ donation is not feasible. This may happen when cardiac function stops and 1) patient never vented, 2) patient cardiac arrests while on a vent, 3) patient in DCD case arrests after the time allowed for successful organ transplant. CDR should collaborate closely with the LifeSource Donation Service Center to evaluate potential gifts prior to speaking with family.

**What in the world do we say?**

Having an important conversation with a family experiencing a devastating loss is difficult and, honestly, many of us prefer to avoid it. But we are the caregivers, we are the providers and we are uniquely positioned to offer hope and healing to a family. When opportunities for saving, lives can be accomplished by caring deeply for our dying patient’s families--- then we have the privilege of being their guide.

Most people, given the opportunity to help someone, want to do it. Your bedrock belief in donation and compassionate care will shape your intention and assist you to bring your best effort and inspiration to the conversation.

The lives of recipients and the lives of families who are making decisions are deeply affected by your skill and connection. Adequate time to spend with the family is important, expert knowledge of donation is needed, and your motivation to communicate to donor families in a way that will help them understand the power of their decision, can make all the difference.
High Stakes Caring

Any number of our daily conversations have high stakes. Attending to them is important and the following guide is useful as you’re planning what to say, how to say it, who to say it to and when to best say it. Likewise, as you plan how to listen, who to listen to, and when best to listen.

We’re recommending eleven areas of focus, no one more important than any others and in no order. Every family is unique and which areas need the most attention will need to be assessed by you- the conversation leader.
ATTEND-TOs DESCRIPTIONS

1. Connection with the family
Does the requester establish an authentic connection with the family? Is relatedness present?

2. Trust
Is the requester trusted by the family? Trust can be gained and/or earned in many ways.

3. Family power dynamic (who’s in charge)
Does the requester figure out who among the family is “in charge” (whether or not that person is the most vocal)? This could be a single person, or the power could be shared among several or all members of the group.

4. Inclusiveness of all (appropriate) family members
Does the requester include all appropriate family members in the conversation, even if they are not Legal Next of Kin (if it is clear that the LNOK wants them there)? Does the requester facilitate the exclusion of people who the family feels should not be a part of the decision-making process?

5. Technical Information / Education
Does the requester understand all aspects of the donation process? Does the requester explain each aspect of the donation process to the family in a clear, concise and accurate way, in a language and at a speed that is appropriate to the family’s current ability to understand? Is the appropriate level of detail given (not too much, not too little)? Does the requester check for understanding?

6. Timing / Pacing
Timing involves bringing up topics at the appropriate time and not sooner. Timing also includes not delaying -- when it is time to address a topic, that topic should be brought up.

Pacing involves the requester’s speed of speaking. Does the requester’s speed match the family’s ability to hear and understand? Speaking at an appropriate pace means not speaking too fast, but it also includes not speaking too slow. Appropriate silence is also part of pacing.
There are no scripts for discussions with high stakes although a general pattern is often seen.

A conversation may begin at or near the time of a patient’s death and may start with an introduction of the requestor, an offer of condolences or sympathy, and a comforting presence. It may include gentle questions to determine what a family understands about their loved one’s circumstance and an offer to clarify misunderstandings or answer lingering questions.

A conversation leader may try to learn more about the patient- their professions, their hopes, how they acted toward others, what they loved and valued. This can lead into a discussion about the possibilities presented by donating organs, tissues, or eyes.

If the family is to make the actual decision about making any gifts they can be told about which gifts might be possible and how they might benefit others. If they are deciding to adjust their end of life plans to allow donation they can be told what will be needed (e.g., to complete medical/social history or change time and place of withdraw of ventilator support).

Once the basic decisions are made a CDR can let family know plans for how family and hospital will work with LifeSource. Lastly, the CDR may continue to offer emotional or spiritual support by arranging time with family or services like Chaplaincy, Child-Life Specialists, or Social Workers.

Check Your Vocabulary: Tips for Sensitive Language

Language plays an important role in the misconceptions and fears about organ, tissue, and eye donation. It’s important for us to remember to keep the feelings of donor families in our mind when we write or talk about donation. The following terminology was approved by the Association of Organ Procurement Organizations (AOPO) Donor Family Council. Please use:

“Recover” organs or “Surgical Recovery” of organs instead of “harvest” or “harvesting” of organs.

The public at large associates the word “harvest” with crops, crows, and combines. This word has a negative subtext when connected with donation. The word “recovery” helps people understand that the removal of a loved one’s organs for transplant is a respectful surgical procedure.

“Deceased Donor” or “Deceased” Donation instead of “cadaver” or “cadaveric”

Today, as more people choose to become living donors, there is a need to distinguish between living and deceased donors. The term cadaveric depersonalizes the fact that a gift was offered to someone upon an individual’s death. Webster defines cadaver as “dead bodies intended for dissection.” It can be very difficult for donor families to hear their loved one spoken of in this regard.

“Mechanical Support” or “Ventilated Support” instead of “Life Support”

There are two ways to determine death: circulatory death (when the heart stops functioning) and brain death (when the brain stops functioning). The term “life support” proves to be a confusing
term when used in conjunction with brain death. When death occurs, there is no support that can make the individual live again. In the presence of brain death, an individual may share the gift of life with others through organ donation. The organs are perfused with oxygen for several hours through “mechanical” support.

“Mechanical” or “ventilated support” are appropriate terms for the support given a deceased person in the event of organ donation.

Positive, affirmative terminology may include:

- Opportunity
- Hero
- Legacy
- Generosity
- Caring
- Giving
- Always thought of others
- Willing to help others
- Ability
- Act of Compassion and Kindness

- Celebrate
- Courage
- Honor
- Hope
- Inspiration
- Life
- Power
- Powerful
- Selfless

Some possible example phrases:

“You, your family and (patient’s name) can touch and save the lives of up to 40 people."

“Donation is a way to make this tragedy into something positive by helping others."

“Thousands of people have been helped by organ and tissue donation and have gone on to live long and happy lives. Robert can touch the lives of up to 40 people today."

“You have the chance to save and enhance many lives today. Robert will always be remembered as a hero to those who are desperately in need of a transplant."

“Donation is one way your husband can be remembered in a way that reflects the goodness of his life."

“Your family and (patient’s name) have the power to keep other families from experiencing the pain and loss that you are feeling."

“Saving lives through donation is a unique opportunity and a gift that, right now, only he can give."

“What an amazing gift that Robert would choose to save the lives of people he did not even know."

“Your loved one has documented their wishes to be a donor so that at the time of their death they could change the lives of people only she could help. “A donation coordinator is going to work with you to fulfill your loved one's wishes.”
“Your loved one’s decision to donate will not only save the lives of people who are waiting but also help make something positive come out of something so tragic. I will be working closely with you and the donation agencies to fulfill your mother’s wishes.”

Family reservation regarding Donor Designation:
On rare occasions, there may be situations where a family has reservations or disagrees with one’s decision. A LifeSource Donation Coordinator will take the lead in facilitating family discussions related to donor designation and will work with the next-of-kin to resolve issues, always keeping the hospital staff informed. If you should encounter family disagreement with donor designation reach out to LifeSource staff to assist with navigation of these uncommon, but complicated, circumstances.

When the family says “No” to donation and Fast “No’s” to Donation

Your role is to support the family and assist them with deciding about donation. A very quick “No” is frequently an uninformed “no”. Very few families have accurate information about donation and you want to make sure they do not regret their decision later because of misinformation.

Listen for what information the family most needs and respond appropriately.

- **Would you be willing to share a bit more of how you made your decision?**
- **In my experience, I’ve learned that some families are worried about funeral arrangements (disfigurement or timing), some worry their loved one won’t be well treated, some are worried they’ll have to pay extra expenses related to donation.**
- **My role is to help you make the best decision at the worst time.**

If the family/legal next of kin decides against donation it is important to
1. Continue to provide compassionate care,
2. Respect their decision, and
3. Thank the family.

Tissue and Eye Exclusive

Tissue and eye donation may occur even when organ donation is not feasible. This may happen when cardiac function stops and 1) patient never vented, 2) patient cardiac arrests while on a vent, 3) patient in DCD case arrests after the time allowed for successful organ transplant. CDR should collaborate closely with the LifeSource Donation Service Center to evaluate potential gifts prior to speaking with family.
Then what happens?

Assuming family wants to pursue donation, let them know that you will be connecting with LifeSource to arrange for a team to begin evaluation process. If organ donation is one of the possibilities, call the Clinical Resource Supervisor (CRS) to learn about travel and time of team arrival.

LifeSource handles all paperwork and may do this with the family in person or over a recorded phone line. If possible, assess with family their plans regarding time at the hospital. This will assist with planning ongoing family connections. Please connect with LifeSource right after our family conversation to make a plan that will best serve the family.

Medical and Social History

A LifeSource Donation Coordinator will always obtain the history from the family after authorization or disclosure forms have been completed.

Obtaining the past medical and social history is an important part of the donor evaluation. The questions asked during this process are like those asked when one donates blood. They identify any high-risk factors for infectious/transmissible diseases that would rule out donation.

Medical Examiner/Coroner Authorization

LifeSource works collaboratively with area Medical Examiners/Coroners to find a balance between honoring the donation wish of an individual or family and the Medical Examiner/Coroner requirements.

It is the responsibility of the Donation Coordinator to call the Medical Examiner/Coroner in the state or county where the donation occurs to obtain clearance for donation of organs and tissues and provide appropriate documentation.

LifeSource Commitment to Donor Families

“You, your family, and your loved one will not be forgotten.”

The gifts of donation so generously given by your loved one and your family are precious, and we take seriously the stewardship of these gifts. Transplantation would not be possible without your generosity, and we thank you for putting your trust in us.”

Donor families will receive support from our Donor Family Advocates in the months and years to come following donation. Donor families receive grief resources, invitation to events and the opportunity to connect with other grieving families whose loved ones gave the gift of life.

Visit the Donor Families pages of the LifeSource website for more information
APPENDIX

Levels of Regulation


- Established the legality of organ and tissue donation and donor designation; as well as the priority of legal next-of-kin for authorization in the absence of donor designation.
- Required that the physician pronouncing or certifying death may not in any way participate in the procedures for removing or transplanting anatomical gifts.
- Protects healthcare professionals from liability associated with donation.
- 1987 Amendment: Required that hospitals establish agreements with an organ procurement organization to coordinate procurement.
- Prohibits the sale or purchase of organs or tissues.
- New classes in hierarchy; expanded to include agents, adult grandchildren and close friends.
- Medical examiner provisions to maximize donation opportunities.
- Requires states to establish donor registries/database that allows a person to designate their donation wishes; must be accessible 24/7 to donation agencies.
- Each state in the LifeSource region has adopted legislation which specifies that the donor designation on a driver’s license represents conclusive evidence of intent to donate at the time of death.
- Donor Designation refers to an individual’s documentation of intent to donate their organs, tissues, and eyes after their death. This may be documented on:
  - A driver’s or chauffeur’s license;
  - A state-issued identification card;
  - Registration on state donor registry;
  - A will;
  - An advanced directive;
  - A donor card or other writing, signed by the individual, intended to make an anatomical gift.
- The donation programs will do everything possible to ensure that the individual’s wishes regarding donation are fulfilled. Donation may proceed with a properly documented donor designation that has not been revoked by the decedent.
Centers for Medicare & Medicaid Services – Conditions of Participation (1998)

- Hospitals must have a signed agreement with an Organ Procurement Organization (OPO), tissue bank and eye bank.
- Hospitals must notify the OPO of all imminent deaths and cardiac deaths in a timely manner (ideally within one hour).
- The procurement agency determines medical suitability for donation.
- The hospital collaborates with OPO, tissue and eye agencies to ensure that the family of each potential donor is informed of their options to donate organs, tissues or eyes or to decline donation.
- To ensure an informed decision, OPO staff or individuals trained by the OPO discuss donation with the family and obtain authorization.
- Hospitals must work cooperatively with the donation programs in educating staff on donation issues, reviewing death records to improve identification of potential donors, and maintaining potential donors while necessary testing and placement of organs and tissues take place.

Uniform Determination of Death Act (1980)

- Federal act states that an individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.

- Since this time, most states, including Minnesota, North Dakota, South Dakota, and Wisconsin, have all adopted similarly worded Determination of Death Acts in their State Statutes.

Legislation regulating transplantation

Organ transplantation is the only medical therapy that is currently regulated entirely by law. From donation to transplantation, the federal government (and to some extent, the state governments) monitor the administrative and financial aspects of this process. These regulations ensure that organs are shared on a fair and equitable basis. In addition, the responsibilities and functions of healthcare professionals are sanctioned and safeguarded by these laws so that their responsibilities may be discharged with assurance and protection medically, legally, and ethically.
Organ & Tissue Donation: Maintaining Confidentiality
LifeSource Position Statement

The clinical experience of donation is often a unique opportunity for medical professionals and hospital employees. News of it is sometimes exciting and intriguing for the public as well. The following guidelines will help you maintain confidentiality in the cases of organ and tissue donation:

- The American Hospital Association confidentiality guidelines apply for all patients including patients who have died, individuals who become donors, donor families, and transplant recipients.

- Donation is a private decision made by donors and family members. Knowledge about this decision and the status of the donation process must be confined to those hospital employees directly involved in the medical care and surgical procedure.

- Many donor families and recipients DO NOT want to know each other’s identity. As such, it is important to respect their right to confidentiality.

- LifeSource practice is to comply with all applicable laws regarding confidentiality.

There are occasions when donation is considered “newsworthy.”

What if the news media inquires about a case?

If the media contacts the hospital public relations department, the hospital spokesperson may find it necessary to make a statement to the press. The following is a suggested statement:

“We are unable to confirm or deny a donation took place. All medical records are confidential. The goal of our hospital is to protect the right of privacy to all patients and their families.”

Although LifeSource and your hospital are unable to offer specific information about donor cases, we can offer general information about organ and tissue donation. LifeSource is always available to provide guidance and is willing to talk with news reporters in your community.

If donor families approach the news media

Donor families may, on occasion, choose to approach the news media with their personal story. If appropriate, hospital staff should help the donor family understand that if news about the organ donation is publicized, they run the risk that the transplant recipients and their families may draw conclusions about the identity of the donor.

Knowing that confidentiality may be jeopardized, LifeSource encourages donor families to wait at least six months to a year before talking with the media. This lapse in time helps to protect the confidentiality of the transplant recipients.

Please call LifeSource, if you have any questions about organ and tissue donation and confidentiality.
LifeSource and Health Insurance Portability and Accountability Act (HIPAA) of 1996

In response to the 1996 HIPAA legislation and hospital’s request for signed Business Associate Agreements, LifeSource developed the following position statement to help hospital staff respond to questions regarding this issue. Please feel free to copy and share the position statement below with any hospital staff who might find it helpful.

**LifeSource Position Statement**

Because the donation and transplantation process requires donation agencies to review confidential patient information or “protected health information”, we are often asked by donor hospitals, “What about HIPAA?” LifeSource should not be regarded as a “Health Care Provider” and therefore, should not be considered to be a “Covered Entity” and subject to HIPAA.

**LifeSource Response to HIPAA Regulations**

The final HIPAA regulations state that the procurement or banking of organs, blood, sperm, and eyes or any other tissue or human product is not considered to be health care. Thus, the organizations that perform these activities would not be considered health care providers when conducting these functions. Consequently, LifeSource should not be regarded as a “Health Care Provider” and therefore, should not be a “Covered Entity” and subject to HIPAA.

The final regulations further state that when an OPO is receiving information from a hospital, it is not considered a Business Associate of the hospital and is not required to comply with HIPAA’s Business Associate provisions. Consequently, LifeSource is not required to comply with HIPAA’s Business Associate provision in carrying out the organ and tissue procurement functions described above.
CDR TRAINING RECORD AND COMMITMENT
Complete this form and bring to in-person training session.

Name: ____________________________________________  
(please print)

Organization: ___________________________________________________  
(please print)

Title: __________________________________________________________  
(please print)

Email: ________________________________________________________  
(please print)

☐ I am signing this letter to express my commitment to the Certified Designated Requestor (CDR) program.

☐ I have read and reviewed this document and will incorporate the additions and revisions into my donation discussions. I will contact the LifeSource Education Coordinator and/or LifeSource Hospital Liaison to discuss my donation discussion experiences.

☐ I acknowledge that I have reviewed the requirements and qualifications for being a Certified Designated Requestor (CDR) and feel that I can meet these requirements.

Signature: __________________________________________________________

Date: ______________________