

## **When One Life Depends On Another:**

### **Family's Understanding and Role in the Organ Donation Process**

One of the first questions a family is faced with after the death of a loved one is the choice for organ donation. Families are approached by an organ procurement organization either beforehand in the matter of a loved one on life support or soon after a doctor has declared time of death. Either scenario is hard on the family. While organ donation seems like just one question of many more to come, it is one of the most important questions to be asked. The family's answer will determine what immediately happens to the deceased's body, potentially leading to a larger impact on people they do not even know. This matter of family consent for organ donation is important, but according to Conor Gilligan, Robert William Sanson- Fisher, and Heidi Turon (2012), when the choice is up to the families, only about 60% consent (Gilligan et al., 2012, p. 313). Unanswered questions about organ donation inhibit the decision of the family's consent during a crucial time. Addressing these issues through better awareness and explanation is one way to work towards increased donor numbers. With better understanding in place, one can more easily visualize the current process and suggest better ways to improve family consent numbers, which will, in turn, increase the number of donations made to change lives.

### **You Are Going to Take What?**

Understanding what organ donation is and what is agreed to when the paperwork is signed is the first step to consenting. Too often the awareness is at a minimum and what donation encompasses is misunderstood. Some people think that the only items that can be donated are the main body organs, often referred to as solid organs. For someone who has an illness or health problems it is often assumed that they cannot serve as a donor because their organs would not be viable. Families of loved ones who have died from a heart attack or some other kind of organ

failure may think the body has been compromised so donation is not something for them to consider. Both of these assumptions are untrue. Organ donation encompasses much more than solid organs only. While solid organs are in short supply and often time the focus for procurement, more of a body is viable for other individuals in need. Donation is often split into two categories, solid organ donation and tissue donation. A better understanding of the differences between donations makes deciding and awareness an easier process.

The most common type of donation is referred to as solid organ donation. This division of donation is often more emphasized because of the overwhelming and immediate need. Solid organ donation is that of the major organs such as heart, liver, lungs, kidneys, and pancreas (Finn, 2000). People who are on the “transplant list” are those in need of these specific solid organs (Gift, nd, para.2). These donations are harder to obtain because there must be a constant blood supply to the organ immediately before it is removed, and the organ must remain undamaged. This is one reason the consenting process has to occur so quickly.

The other consent option is for tissue donation, which includes a broad range of materials such as eyes, corneas, veins, valves, skin, and bones (McKenna, 2012, p.2). Tissue donation is considered “life enhancing” as it can be used on patients who have been crippled or disfigured by disease or a tragic accident (Atwood et al., 2012, p. 26; McKenna, 2012, p.1). The most common type of tissue transplant is that of the corneas, giving someone the ability to see again (Finn, 2000, p. 107). While these materials are not used as readily, like in the immediate transplant of solid organs, they still need to be obtained within the first twelve to twenty four hours after death (Atwood et al., 2012, p. 26). Even in the case of tissue donation, the urgency for consent is still a major factor.

Despite its importance, tissue donation is often overlooked. Families and individuals do not realize that this type of donations is possible. Others may think, “I’m just one person; they won’t miss one donation,” but this way of thinking is uninformed. When my father passed away recently of a heart attack, my family consented that his body be used for donation. After the Gift of Life performed the procedures necessary, they sent us a letter detailing the types of tissues donated. Among the listed tissues were his bones. We were informed that from his donation of bones alone that fifty to one hundred patients could be treated in various ways (McKenna, 2012, p.1). The “I’m just one person they won’t miss” mentality should change to “I am one person who will make a difference.” The choice to donate something as simple as tissue has a broader impact than most people realize.

Understanding the difference between organ and tissue donation is important, but families tend to still have underlying concerns about the process. They worry that consenting to donation means their loved one will be disfigured, but this is not true by any means! In the procurement process, the body of the deceased is treated with respect, and the organs are taken in an inconspicuous manner (Finn, 2000, p.15). For example, they take skin from places that will not be seen such as the belly and back area, and bones are removed in a way that does not deform the overall body shape. As a result, families are able to view their loved one in an open casket service just as they remember him or her.

Another worry individuals may have about making the decision to donate prior to death is that the decision will affect the type and amount of medical care they receive as patients. This, however, is not at all true. The doctors working on the patient are separate from the transplant process, and only after death has been determined is the organ procurement group contacted. Once these types of concerns are addressed, the decision to donate is made a little easier.

### **Choices, Choices, Choices**

Before donation can be started it is of general consensus that “procurement of organs postmortem is only allowed if the deceased or his or her next of kin consented to organ donation” ( Coppen et al., 2010, p. 836). After the individual dies, therefore, the family must make the final decision with regards to organ donation. When the loved one’s wishes are not made evident prior to their death, the family is left with the entire decision. Making the choice personally to be a donor eases the decision process for the entire family. There are several different ways this can be done. The most common way is on your driver’s license. Another way to consent is to officially register on-line. This process is also quick and simple. Once registered as a donor, some people prefer to carry on their person a donor card. Individuals often use this card as a way to tell their families about the decision they have made to be an organ donor (Gilligan et al., 2012, p. 314). In the case of death when there is no next of kin to contact, these forms of consent are legal, allowing the individual to be a donor. When the family is there to be asked, having made the decision ahead of time makes the process of obtaining consent easier and less stressful for the family.

Whether the deceased patient has made the decision for organ donation official or not, the family is still consulted. The organ procurement organization is not going to come in and take the body from the family just because the individual had indicated donation prior to death. They first talk to the family about organ donation and the process or steps to be taken. It is important that the family be well informed to make the best decision for them. Organ procurement organizations stress the wishes of the deceased with the family if they are known so the family can make their decision the way their loved one had intended (Kalkbrenner, 2012, p. 254). They approach the family not as much in the way of asking for consent but seeking to honor what their

loved one wanted. The choices made by the individual are official, but the final decision is given to the immediate family. Some families, whose loved one has previously expressed their desire to be a donor, still choose to decline organ donation. Even though the loved one's previously documented decision is legal, the organ procurement team will not force it into practice against the family's wishes (Atwood et al., 2012, p.25). In any case, the family's final decision can be clearer when their loved one's wishes are known and the process can move along faster so the family can deal with other questions and arrangements.

The decision made by the family is final. This is why family consent is so important for increasing organ donors. The consent of the family is the last chance for donation to be made. Organ procurement organizations focus much of their efforts on getting to the family in a timely manner so a trusting relationship can be formed and all a family's questions might be answered. With better understanding, the family can make a more informed decision about donation.

### **“Are You Sure?”**

When families are confronted with the decision for donation, sometimes the ability to obtain a “yes” is not as easy as it sounds. All kinds of variables influence a family's decision, and it is not until they are addressed, or at least acknowledged, that families can be better served and the number of donors increased.

One of the biggest variables that families and organ procurement teams are faced with is time. It is important that the organ procurement organization and team be notified as soon as possible, giving them more time to get to the family to start building a relationship with them. Studies done pertaining to time found that “total time spent with families was found to be significantly associated with favorable consent” (Salim et al., 2011, p. 735). Increased time allows families to better process their decision to consent for donation.

The type of death and the timing or expectancy also greatly affects the way a decision is made. When the death is sudden, the family goes through that initial shock and disbelief, and it is harder for the family to disconnect the idea of organ donation from their loved one's death. In this case, the organ procurement team has less time with the family, and the whole process has to move along much faster. In the occurrence of death a little more expected, like in the case of brain death of a patient being on a respirator, the emotional and grieving process starts sooner giving the family more time to cope and come to terms with the inevitable death before being faced all the big questions (Gilligan et al., 2012, p.313). Neither way of dealing with the issue is not easy, but the timing can impact the families thought process. Interestingly, though the process of obtaining consent seems more chaotic in a sudden death situation, research has shown that "Consent rates were significantly lower for medical (51%) patients [expected] than for trauma (67%) patients [sudden]"(Brown et al., 2010, p.449). Either way, timing can have an effect, and it is important that the organ procurement team adjusts their approach accordingly.

Another big barrier for families is the desire to consent the way their loved one would choose. For families who know what decision their loved one wanted to make the choice is not as tasking. On the other hand, when the family is unaware of their loved ones wishes they might struggle with the correct way to answer. The last thing the families want to do is make a decision their loved one would not want. By making the personal decision about donation ahead of time much of the worry and complexity to the decision process can be removed for the family. Making the decision or signing the donor card is not enough though, however. Families need to be made aware of how their loved one feels. Something could happen to an identification card indicating the decision to donate. If the individual has never discussed or made their family aware of the decision the family is back to where they started with worrying about the right

choice (Finn, 2000, p.16). When the family has prior knowledge of their loved ones wishes the decision making steps can be easier and the family can grieve and begin the consoling process without the worry of disrespecting the deceased. This is one barrier that will not change unless the individual makes the choice themselves. No one can force a person to decide but things are made drastically easier on the family when the choice has already been made.

Even after the decision is made by the family consenting to organ donation there are still major factors that could influence or give the family an uneasy feeling about ever consenting again. A deterrent families might experience after the decision to donate is how the organ procurement organization handles the family's situation. When the team treats the family rudely or creates more problems the family will be less inclined to agree to organ donation should the time come up for them again. Sometimes it seems like the organ procurement team is working on their own time causing other aspects to be more difficult for the family. Considering that organ procurement can be a timely process, it is even more important that the organ procurement team be open and informative to the family when they are making the decision to consent.

### **Improving Self for Others Benefit**

The choice of organ donation does not need to be a hard step for the family and can also be a source of comfort. This comfort can only come when the family has been informed and has a strong foundation of knowledge to go off. With this knowledge, better choices are made and can even be done in advance so the family already knows how to answer when the time comes. Since the family is responsible for the final decision it is important to be prepared. Death does not discriminate based on age, so it is never too early to talk about personal feelings regarding donation. Family's choices are important so why not make it a family discussion before one is are gone and the rest of the family is left to decide for them.

It can be difficult to fully comprehend the number of individuals on the transplant list waiting for families to make the “yes” decision. Imagine for a minute the University of Tennessee Neyland Football Stadium in Knoxville Tennessee. It is a University of Tennessee home football game and the stadium is packed with people! When the UT Stadium is at full capacity, they are capable of seating 102,544 people (About, nd, par. 1). Now consider, currently there are 116,497 people on the organ transplant waiting list in the United States alone (Health, 2012, p.1). That is almost 14,000 more people than could fit into the University of Tennessee Stadium! The number of people waiting is extensive and the number grows every day with another individual being added every ten minutes (Donate, nd, para. 2). For this reason, family consent is essential. The number on the waiting list cannot decrease until more families consent to the donation process. This one question—a question that seems just like all the others when you are faced with the death of someone you love—effects more people and lives than can be imagined. Once the family more clearly understands the process, the overall organ donor numbers will increase. Organ donation is truly the gift that keeps on giving. Someone’s life can be changed dramatically and hope for a better life restored. Are you ready to give the “gift of life” when the time comes?

Dedicated to my Daddy, my Strength, and my Best Friend – Lloyd Nyman Jr.