

THINKING ABOUT ORGAN TRANSPLANTS

Organ transplantation is a medical treatment that has grown quickly in the past years. The types of organs that can be transplanted has increased, and the surgery techniques, the success rates, and the effects of the lifelong medicines have improved. In the minds of some people, certain types of transplant have moved from experimental to standard therapy. This is a confusing and changing line. There are also moral or religious meanings of transplant for some families that are extremely important.

Some basic questions about how you view transplant that are helpful to discuss with your child's doctor:

1. What is your basic belief about organ transplants, including moral or religious?
2. What are the alternatives to transplantation?
3. What will happen if a transplant is not done?
4. Is the doctor recommending a transplant for your child?
5. How do transplant waiting lists work?

Because transplantation is still a relatively new treatment and the information is changing rapidly, it can be hard to focus on some of the relevant questions parents need to understand to make the best decision. Here are some questions that will help you have all the information you need to make the best decision you can for your child:

1. What, if any, time constraints exist regarding the possibility of transplant?
2. What are the survival statistics in general for children, and especially infants?
 - A. Survival from surgery
 - B. One year after surgery
 - C. Each year for the five years after surgery (cumulative mortality table)
 - D. If anything is known about long-term survival
3. Are there factors or conditions for this particular child that suggest adjusting the survival estimate up or down?
4. What information exists on morbidity for survivors? That is, what is the quality of life for those who do survive?
 - A. In the first three weeks after transplant?
 - B. In the first three months after transplant?
 - C. In the years after transplant?
5. What actual medical cares are involved after the transplant, including medicines, routine visits, and regular treatments?
6. What is the likelihood of receiving an organ, and how many children of all those listed die while waiting for transplant?
7. If the transplant would be done in another city, do you have to live there before the transplant? Do you have to live there while waiting for the transplant? Do you have to live there after the transplant? If so, for how long?
8. What are the finances of the transplant, and who pays for them now and in the future? Costs to consider are:
 - A. The transplant itself.
 - B. Ongoing medical treatment.
 - C. Associated expenses (travel, food, lodging).
 - D. Accommodations for siblings.

9. Is the transplant experimental or very new for this age or disease?
 - A. Is it part of a formal research study?
 - B. Is there any part of the procedures (for example, medicines afterwards) that are part of a formal study?
 - C. If the transplant itself is not experimental, is it considered standard treatment for this disease or this age group?
10. What are the alternatives?
 - A. Is there any other curative, therapeutic alternative?
 - B. There is no curative treatment, but is providing hospice or comfort care an option?
11. Recognizing that the parents are the decision-makers, it is helpful to have specific recommendations regarding proceeding with transplant. What specific recommendations do the physicians and other health care team members make?
 - A. The transplant physician
 - B. The pediatrician or managing physician
 - C. Sub-specialists
 - D. Nursing and other team members
12. Are there specific family or cultural issues that the family should consider in addressing the possibility of transplant?

Talking with your child's doctor, your family, and advisors is extremely important as you make decisions for your child. In addition to your health care team, you can receive assistance from an ethics consultant in gathering and thinking through these complicated issues.

