

TRANSPLANTS FOR CHILDREN WITH DISABILITIES: INFORMATION FOR PARENTS

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Organ Transplants for People with Disabilities



Before 1990, an intellectual disability prevented a person from receiving an organ transplant.¹ Today, according to statistics from the Scientific Registry of Transplant Recipients, many children with intellectual disabilities are on the United Network for Organ Sharing (UNOS) waiting list and receiving transplants, and the

survival rates are comparable to the general population.²

The Americans with Disabilities Act (ADA) prohibits discrimination against people with disabilities, and directs medical professionals to provide the same access to organ transplants.³ Acceptance or denial onto the waiting list is determined by medical professionals at individual transplant centers. A child can be denied at one center and wait-listed at another.

One important consideration when a

patient is assessed for transplantation is compliance following a complex medical regimen. Having a supportive family member available to oversee compliance of medication and to adhere to dietary restrictions help determine if a child is placed on the waiting list.⁴

One parent explained “parents are the only ones with all the knowledge” when referring to the many physicians and sub-specialists her child sees for medical care. Her advice: “Ask questions and take lots of notes. You are your child’s best advocate!”

For children with disabilities, having a parent or caregiver who is able to manage the many aspects of the transplantation process is a critical piece when a child is evaluated for a transplant and put on the UNOS waiting list for an organ transplant.



How to Advocate for your Child

Before Transplant:

When speaking with your primary care physician (PCP) and other physicians, it is important to note your child’s rights for access to transplantation and referrals for further medical care. You may be faced with doctors who discourage transplantation. Your child is entitled to the same quality of life as any other child. Your family may seek a second opinion to ensure your child is receiving optimal medical care.

Transplant Evaluation:

When being evaluated for a transplant, in addition to a medical work up, your child is assessed from a psychosocial standpoint. During this process, the transplant team assesses the family’s coping skills, social supports and resources. It is important for the family to demonstrate their ability to care for the child in three areas:

Medically: the ability to comply with the complex medication and diet regimen.

Socially: the family has an intact support system to care for the child and the family’s needs.

Financially: the family has resources and insurance to help provide for the child’s transplantation process.

Post-Transplant:

Families must show a willingness to comply with new medications, diet, and follow up for necessary medical care and appointments.

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1. Martens, M.A., Jones, L., Reiss, S. (2006). Organ transplantation, organ donation and mental retardation. *Pediatric Transplant*, 10(6), 658-64.

2. Scientific Registry of Transplant Recipients. October 21, 2009.

3. Orentlicher, D. (1996). Psychosocial assessment of organ transplant candidates and the Americans with Disabilities Act. *General Hospital Psychiatry*, 18(6), 5-12.

4. Collins, L., Holden, E., and Scheel, J. (1996). Cognitive functioning as a contraindication to organ transplant surgery: Dilemmas encountered in medical decision making. *Journal of Clinical Psychology in Medical Settings*, 3(4), 413-22.

Important Things to Know about Transplantation

“HAVE YOUR OWN
OPINION OF WHAT IS
BEST FOR YOUR
FAMILY AND YOUR
CHILD WHEN
LISTENING TO
MEDICAL ADVICE”
- PARENT OF A CHILD
WITH A DISABILITY



When waiting for an organ transplant, parents need to be reachable at all times so the medical staff can contact you when your child matches for an organ.

When your child does receive a transplant, it is important to

remember that your child is trading one disease for another set of medical needs. With this in mind, parents still describe life with a transplant as “much better.”

For children who have undergone dialysis, families stated that quality of life is improved and their child is able to participate in many more activities.

In the immediate weeks after an organ transplant, medical appointments are frequent, but they slowly taper off as time passes.

Your child will always have to take several medications to keep from rejecting his or her new organ, but the medications also become fewer as time passes.

It is important to always be watchful of new symptoms, as you want to be mindful of signs of organ rejection. If you notice any changes in your child, contact your physician immediately.

How to Talk to Your Child about Transplant

Many organizations have produced children’s books specific to the organ being transplanted.

Making a personal storybook of your child’s procedure can help a child visualize the steps that will occur. Children can add their own drawings and photographs of themselves to make the book more personal.

Involving Child Life Specialists in hospitals can be helpful. These professionals are trained to work with children and help educate them about medical procedures. They can provide child-friendly descriptions about transplantation and use adaptive toys to help place your child at ease.

If your hospital has a Family Learning Center, there may be

resources available for families, including information for siblings of children who receive transplants.



“GET A LIST FROM
THE DOCTORS OF
EVERY SINGLE THING
YOUR CHILD CAN AND
CANNOT EAT TO MAKE
THE PROCESS EASIER
FOR YOURSELF”
- PARENT OF A CHILD
WITH A DISABILITY

Medication and Diet

Each organ transplanted has different dietary and medical restrictions. It is helpful to discuss with your doctors what the exact restrictions and allowances are for your child.

Many parents state using a routine to help your child take medications can be effective. This includes singing songs, playing music or telling stories to help ease the mood.

Taking medicine can also be turned into a game. Token charts with rewards have also been shown efficacious to help children both take medicine and eat appropriate foods.⁵

One parent stated “teach your children to learn things for themselves, including taking their medications; you want to teach your child independence.”

Another parent described the importance of understanding your child’s limits when taking medication. She recommended brainstorming with the medical team to devise different ways to administer the medications, as it can be overwhelming to administer the many medications necessary for a child to take all at one time.

5. Magrab, P. R., & Papadopoulou, Z. L. (1977). The effect of a token economy on dietary compliance for children on hemodialysis. *Journal of Applied Behavior Analysis, 10*(4), 573-578.

Tools to Detect When Your Child is in Pain

Using photographs of your child’s facial expressions can help denote the different emotions your child is experiencing.

Child Life Specialists may also have access to the Wong-Baker FACES Pain Rating Scale that uses cartoon faces expressing pain on a scale from 1-5.⁶ This can help children articulate the level of pain they are experiencing.

Drawing a map of your child’s body on paper and coloring in different areas where he or she is experiencing pain can be a helpful visual aide for your child. This tool can also help parents track their child’s pain from day to day. One parent points to each body part to achieve a better understanding of where her child’s pain is located.

This parent also charts her child’s daily medication intake and notes changes in appetite, mood, and/or behavior. This allows her to notice if there are any patterns or changes in her child’s conduct.

One parent stated a key indicator that her daughter was in pain was a change in her sleeping and eating habits. Being in tune with your child’s daily routine can highlight when something is wrong.

Wong-Baker FACES Pain Rating Scale⁶



Family and Self-Care

Taking time for yourself is a very important part of caring for your child. Make sure you set time aside for self-care. Ask friends and family to help take care of your child or other siblings.

Finding support groups for yourself and your children can be a positive way for your family to express hopes, concerns,

frustrations, and joys with other families in similar situations.

One parent stated when her other children saw the restrictions their sibling had to follow, they had a “heightened appreciation of the simple things in life.”

Include your other children in conversations about your child undergoing transplant. Keeping these children involved and informed is key to reducing anxiety and helping them to feel like a part of the family. When these siblings are old enough, discuss with them future plans for your child with a disability.

“BE HONEST WITH YOUR OTHER CHILDREN ABOUT THE TRANSPLANT PROCESS AND COMMUNICATE THE INFORMATION IN AN AGE APPROPRIATE MANNER”

- PARENT OF A CHILD WITH A DISABILITY

School Programs

Involving school in the process can help children feel less removed from their daily activities. One program that has been created to assist children in hospitals for an extended period of time is called “There’s a monkey in my chair.” This program sends a stuffed animal to sit in your child’s chair at school while your child is undergoing his or her transplantation. It encourages classmates to write letters and draw pictures of activities that

are occurring in the classroom so your child remains included from afar. For more information, please visit: <http://www.monkeyinmychair.org/>

Early intervention programs are also available for children 0-3 years of age. This program provides a range of in-home services for children to help them recover from surgery. Children with disabilities also independently qualify for this service.



6. Hockenberry MJ, Wilson D: *Wong’s essentials of pediatric nursing*, ed. 8, St. Louis, 2009, Mosby. Used with permission. Copyright Mosby.

TRANSPLANT TERMS:

- ◆ UNOS: United Network for Organ Sharing
- ◆ OPTN: Organ Procurement and Transplant Network
- ◆ NOTA: National Organ Transplant Act
- ◆ OPO: Organ Procurement Organization
- ◆ COTA: Children’s Organ Transplant Association

The Federal Law



The ADA was created to prohibit discrimination against people with disabilities. The ADA is a federal law that clarifies that people with disabilities have equal access to employment, public transportation, public facilities, and telecommunication services.

The ADA law may become relevant to your child’s transplant process when looking for transportation to and from the hospital. It will also become relevant when your child becomes of working age.

The Individuals with Disabilities Education Act (IDEA) mandates that all students with a disability have an Individualized Education Plan (IEP) created for their educational needs.

When a child with a disability undergoes a transplant, he or she may need to take time off from school to recuperate. During this time, children can receive homeschooling to help keep up with their studies.

The Family and Medical Leave Act (FMLA) entitles parents to take a leave of absence from work when their child has a serious medical illness. Some parents are also granted an extended leave through this act to care for their child undergoing a transplant.

If one of the parents is also the organ donor, that parent is entitled medical leave to recuperate from his or her own organ donation.



Useful Websites

<http://www.cota.org>

Children’s Organ Transplant Association helps fundraise and provide family support.

<http://www.childrensdisabilities.info>

Articles and information for parents of children with disabilities.

<http://www.ntafund.org>

Organization that helps families fundraise and gives information on family support during transplantation.

<http://www.unos.org>

United Networks for Organ Sharing provides information on transplantation.

<http://www.organdonor.gov>

Government website addressing questions related to the transplantation process.

<http://www.transplantliving.org>

Information and resources about the different stages of transplantation.

<http://www.transweb.org>

Games and information for families on transplantation.

<http://www.disabilityhelpsite.com>

Information for parents on resources for children with disabilities.

<http://www.optn.org>

Organ Procurement and Transplantation Network with information on transplantations and the organ waiting list.

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