



**TRANSPLANT UNWRAPPED  
PRESENTS:**

**Preparing for  
Your Child's Wait,  
Transplant, and  
Hospital Stay**



**Transplant  
UNWRAPPED**

# The Transplant Waitlist

The **amount of time your child will wait** for their transplant is unpredictable and can **vary greatly**. To get a better sense of how long the wait will be, you should ask your child's care team average wait times for the particular transplant and organs your child is listed for; but, you must have the understanding that it is just an estimate and the transplant team has no control over when the transplant will happen.

## Emotions While Waiting

Waiting for a transplant can be emotionally draining for you and your child. You and your child may experience a wide **range of emotions**, including:



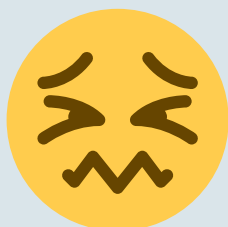
**Fear:** Will my child die before they receive their transplant?



**Guilt:** Another child must die for my child to receive their transplant.



**Hope and Excitement:** My child's transplant can help make them better.



**Frustration and Anger:** Why is it taking so long to get the transplant? My child is suffering.



**Anxiety or Anticipation:** When will the call come for my child? Did I miss "the call?"

## Coping While Waiting

1. **Use support systems:** Family, friends, and your child's transplant team are there to support you and your child. Talk to the people around you and express your frustrations and fears. Allow your child to express their frustrations and fears. It is not healthy for you or your child to keep everything bottled in. Talking about what is bothering your child can help ease their anxiety and fears. Let your child know it's okay to talk about their thoughts and feelings.

# Coping While Waiting

- 2. Live life as normally as possible:** While waiting, you should still make plans for your child and do things with friends and family.
- 3. Learn and research:** Part of the frustration with waiting comes from the fear of the unknown, not only from not knowing how long your child will wait but also from not knowing what to expect from their transplant. Educating yourself and understanding what to expect for your child will hopefully empower you and make you feel more comfortable in your current situation. Depending on your child's age, provide age-appropriate information on what to expect when it comes to their transplant. Avoid overprotecting your child or keeping important information from them.
- 4. Get help:** If you or your child are struggling with the wait or any other difficult stresses, it may be worth speaking with a counselor, social worker, or psychiatrist.

## Talking to Your Child About the Hospital

What you tell your child and the way you say it can have a big impact on your child. You should encourage your child to ask questions and provide simple and honest answers. Consider your child's age and comprehension level when deciding when you should tell your child about the stay, the terms used in your explanation, and the amount of information you tell your child.

### When to Speak With Your Child



**Toddler**  
(1-3 years)

Talk right before going to the hospital as toddlers have limited understanding of the concept of time.



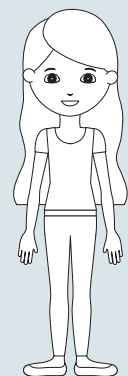
**Pre-School**  
(3-5 years)

Talk with them one or two days prior to going to the hospital.



**Elementary School**  
(5-12 years)

Talk with them about one week in advance. This gives them time to ask questions and develop coping strategies.



**Teen**  
(12-18 years)

Talk with them from the very beginning, allowing them to process information, educate themselves, and ask questions.

# Communication While Waiting

**Communication** with your child's transplant team is **very important while waiting** for transplant. If any vital information changes, you must immediately contact your child's transplant team of these changes:

- If your **child's health insurance changes**, promptly inform the team- not informing them may jeopardize your child's transplant care.
- If your **address or phone number changes**, you must promptly inform your child's transplant team.
- If your **family is leaving the area** for some reason, always inform your child's transplant team of where you are going and how long you will be gone. The team will inform you if this warrants your child's placement on status 7 or 'hold' status.
- If your child is still **seeing doctors other than their transplant team**, you must inform your child's team if any medication changes are made- this includes both over-the-counter medications and prescription medications.
- Make sure you are always able to **contact your child's transplant team** at any time. Always **carry the transplant center's contact information**, including the phone number, name of your child's transplant coordinator, and/or social worker, and have access to a reliable phone.

## Being Prepared for the Call

1. **Have a bag packed** that you can take with you when your child gets the call for organs. Make a list of additional items you may want to 'grab' on the way out the door (such as a cellphone, chargers, headphones, your child's favorite toy or blanket etc.) that you may not be able to pack ahead of time. Use one of the packing lists at the end of this handout to help check off what you have packed.

2. If you **have pets or other children**, have a plan in place of how they will be taken care of when your child gets the call.

3. Make sure you have a plan in place for someone to take care of your mail/ newspaper/ plants etc.

4. **If your child is in school**, speak with the school's administration and teachers to create a plan of how schoolwork will be handled when your child receives the call and transplant.

# Being Prepared for the Call

5. **Plan for being away from work.** If you normally work, explore your options for having time off from work when your child receives the call. This may include the Family Medical Leave Act (FMLA), employee assistance programs, COBRA insurance, and short- and long-term disability programs. The **human resources department** of your employer should be able to answer any questions regarding the benefits that might be available to you.

6. Make a **plan of how you will communicate with family and friends** when your child receives their transplant. For example, many families choose to create Facebook groups, or a page on sites like CaringBridge.org, to provide group updates.

7. **Arrange travel** for when your child receives the call. Make sure your mode of transportation can get you to your child's transplant center in the amount of time required by your transplant team. For lodging, explore the options around the transplant center,

8. **Arrange lodging** for when your child receives the call. Inquire with your child's transplant center social worker to see if there is a transplant house or Ronald Macdonald House that you and your family can stay at while your child receives their transplant. If not, explore other lodging options, such as hotels and apartments. Ask the transplant social worker if any nearby hotels offer special rates to patients.

## Being Prepared: Maintaining Health

1. Make sure your child follows their **medication regimen** as prescribed.

2. **Optimize your child's nutrition** to ensure they continue to follow their growth curve and maintain well-being. This may include parenteral nutrition (PN), enteral nutrition (tube feeds), and/or eating some food by mouth. **Working with a dietician** before your child's transplant is of the utmost importance.

3. **Encourage your child to participate in activities and exercise as tolerated.** After transplant surgery, your child will become de-conditioned from the surgery and being in the hospital. The stronger going into the transplant, the stronger they will be coming out. Staying involved in activities also helps to keep up both you and your child's morale during the difficult waiting period.

# Preparing for the Hospital Stay

Hospitals vary on the facilities they provide for caregivers and family members. Check with your child's social worker or another member of the care team to determine what is offered (i.e. bathroom or showering facilities for caregivers, can you stay overnight in the room with your child, etc.)

You should check with your child's care team to see what you should and should not bring with you to the hospital. In general, most hospitals request that you **do not bring**:

- **Electrical items**, such as small appliances, that can be a fire hazard.
- **Medications from home.** You **should bring a list** of your child's medications, but leave the actual medication at home unless specifically requested by the care team.



Aside from physical items, you need to bring a **list of important information** for you and your child, including:

- Your driver's license or another form of photo identification.
- Your contact information (name and telephone number) and any other emergency contacts.
- Your child's Social Security number.
- Contact information for your child's primary care physician and any other physicians you would like your child's records to be sent.
- Insurance information for your child.
- An up-to-date list of the medications your child is taking.

## Tips From Transplant Recipients and Caregivers

1. **Bring an extension cord.** Oftentimes the outlets in the hospital room are in inconvenient places, for both you and your child. An extension cord makes sure all of those important chargers can be easily reached!
2. Pack **clothing that can be layered.** The temperature in a hospital is unpredictable. For the comfort of both you and your child, make sure to bring multiple layers of clothing.
3. Do not forget about your own comfort and well-being. As a caregiver you must **take care of yourself** to ensure you can be at the top of your game when your child needs you.

# A Kid's Hospital Packing List

- SLEEPWEAR
- SOCKS & UNDERWEAR
- TOILETRIES
- JACKET OR SWEATSHIRT
- SHOES
- FAVORITE TOY OR STUFFED ANIMAL
- BOOKS
- COMFORT BLANKET OR PILLOW
- COLORING BOOKS AND CRAYONS
- PICTURE OF FAMILY
- GADGETS (EAR BUDS, VIDEOS?)
- FAVORITE SNACK- FOR WHEN YOUR CHILD CAN EAT AGAIN.





# A Caregiver's Hospital Packing List

- COMFORTABLE CLOTHES & SLEEPWEAR
- SOCKS & UNDERWEAR
- JACKET OR SWEATSHIRT
- SHOES
- TOILETRIES, TOWELS, TISSUE
- BLANKET & PILLOW
- INSULATED CUP WITH LID
- FOOD AND SNACKS
- BOOKS, MAGAZINES
- GADGETS (EAR BUDS, IPAD, COMPUTER)
- CHARGERS
- YOUR RX MEDICATION, VITAMINS, OVER-THE-COUNTER MEDICATIONS





## Interested in learning more?

Visit us on our [Main Website](#), where you will find helpful webinars, downloads, and support systems. In addition, our [Parent's and Caregiver's Page](#) on the Transplant Unwrapped Kid's site also offers helpful downloads and information.

## Get in Touch!



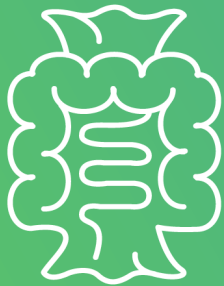
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[www.transplantunwrapped.org](http://www.transplantunwrapped.org)



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2. Talking with your kids about your transplant. National Kidney Foundation. [https://www.kidney.org/transplantation/transaction/TC/summer09/TCsm09\\_TalkingwithYourKids](https://www.kidney.org/transplantation/transaction/TC/summer09/TCsm09_TalkingwithYourKids). Published August 12, 2014. Accessed July 7, 2021.

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