

# PSYCHOSOCIAL CARE

EMOTIONAL AND BEHAVIORAL NEEDS BY DEVELOPMENTAL AGE



Your child's well-being and emotional health after transplant is just as important as his physical health and recovery. Here are some things to do to support positive adjustment following transplant for your family.



**Establish and maintain a daily schedule:** Keeping to a routine not only helps to keep track of med times and appointments, but it will also help your child adjust emotionally. Children and teens tend to cope better when they know what to expect and are better able to manage surprises or challenges when they feel grounded in their daily routine.

This routine should include a **consistent sleep schedule**. Anchor your child's day by setting a daily bedtime and wake time. A consistent sleep schedule will help your child with mood, fatigue, and compliance. Children and teens are much more likely to accomplish tasks and goals when they are adequately rested and feel emotionally stable. Keep in mind that immediately following transplant, your child may be on certain medications, such as steroids, that make falling and staying asleep difficult.



**Get up and moving!** Once medically able, encourage your child to return to normal physical and social activities. This can be challenging, particularly if you don't return home right away, but work with your child to come up with a list of desired activities and get creative! Take walks, engage in family outings, explore outdoors, and call family and friends. Try to do one thing every day to combat boredom and enhance emotional functioning. Talk to your transplant clinic team about what activities are safe for your child.



Your routine will also include a **daily medication schedule and other routine care**. Setting alarms, using medical apps, or a written checklist will ensure that your child is receiving the right care at the right time. Involve your child in their care in a developmentally appropriate way from the beginning. This will help to teach your child independence with their care so they can take over when appropriate.



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Developmental Age	Ways to Involve Your Child in Care
Preschool (3-5yrs)	<ul style="list-style-type: none"> <li>● Give appropriate choices about the order of their care/medications when allowed (e.g., first prograf, then bicarb, then nystatin)</li> <li>● Build medications into the morning/evening routines to create a healthy habit around medication-taking</li> <li>● Take charge of other daily healthy habits (e.g., brushing teeth and hair, bathing)</li> <li>● Allow access to reward for completing care</li> </ul>
Young school age (6-9yrs)	<ul style="list-style-type: none"> <li>● Give appropriate choices about the order of their care/medications when allowed (e.g., first prograf, then bicarb, then nystatin)</li> <li>● Hold supplies needed for care</li> <li>● Check off items on care checklist as they are completed</li> </ul>
Older child (10-12yrs)	<ul style="list-style-type: none"> <li>● Set alarms for care needs</li> <li>● Reporting symptoms</li> <li>● Begin to learn medications taken at each time point</li> <li>● Ready supplies for feeds, ostomy changes (as needed)</li> </ul>
Adolescent (13-17yrs)	<ul style="list-style-type: none"> <li>● Report symptoms to caregiver and/or coordinator</li> <li>● Help caregiver fill pillbox</li> <li>● Notify caregiver when bottles near empty</li> <li>● Write down questions to ask doctor at upcoming appointment</li> </ul>
Young adult (18+yrs)	<ul style="list-style-type: none"> <li>● Report symptoms to coordinator</li> <li>● Schedule medical appointments</li> <li>● Help caregiver fill pillbox or fill box themselves</li> <li>● Work with caregiver to refill medications</li> <li>● Write down questions to ask doctor at upcoming appointment</li> </ul>



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**Create a plan for transition home!** When you and your child are nearing discharge from the hospital, it will be helpful to think about a plan to return to life at home. Home will now incorporate many aspects of your newly established medical routine in addition to other responsibilities such as work. It is important to think about and create a plan to navigate these obligations, along with required follow-up transplant care in the hospital. A social worker can help your family develop a plan to help ease this transition process.



**Talk with your child about transplant:** It is common for children and teens to shy away from talking about themselves especially when it comes to their medical care. It can be difficult for your child to talk about medical terms and feelings that they do not understand themselves or have not yet fully processed. It is important to allow space for your child to discuss their transplant experience, express emotions (both positive and negative) about what they have been through and ask questions as they arise. A child life specialist or psychologist can help your child learn to cope with these emotions and to learn developmentally appropriate information about their diagnosis and the transplant process.



**Practice telling your story:** Your child can expect to be asked a lot of questions about their transplant. Friends and classmates will likely be very interested in knowing your child's story or be curious about scars or other aspects of their physical appearance, so it is a good idea for you and your child to practice answering these questions or politely declining to talk about it. Responses can range from declining to talk about it (e.g., "I just had a transplant. I am feeling better. I don't want to talk about it."), to developing a "30 second elevator pitch," to a class presentation about their journey. Your child life specialist or psychologist can help your child come up with additional responses.



**Address behavioral and emotional needs:** There are a myriad of reactions that children and teens can experience after transplant. The chart below lists common emotional and behavioral responses for each developmental age group. It is important to address any emotional support needs or behavioral issues that your child experiences post-transplant to promote healthy long-term adjustment.

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Developmental Age	Common Emotional Responses	Common Behavioral Responses
Preschool (3-5yrs)	<ul style="list-style-type: none"> <li>• Feel loss of control</li> <li>• Fear of routine medical interventions such as taking medications, vitals, or lab draws</li> <li>• Emotional outbursts are typical (anger, sadness, tantrums)</li> </ul>	<ul style="list-style-type: none"> <li>• Not eating</li> <li>• Trouble following directions</li> <li>• Difficulty sleeping (not wanting to nap or follow bedtime routines)</li> </ul>
Young school age (6-9yrs)	<ul style="list-style-type: none"> <li>• Feel loss of control</li> <li>• Feeling inferior - sense of guilt or wrongdoing when unable to participate in care (e.g. not able to sit still for lab draw, throw up medications)</li> <li>• Medical anxiety - anxious about medical interventions such as lab draws, biopsies, anesthesia</li> </ul>	<ul style="list-style-type: none"> <li>• Attempt to gain control by not eating, refusing medications, etc</li> <li>• May not want to participate in normal activities</li> <li>• May be avoidant of medical discussions, pretend not to listen</li> </ul>
Older child (10-12yrs)	<ul style="list-style-type: none"> <li>• Feel loss of control</li> <li>• Medical anxiety - anxious about medical interventions such as lab draws, biopsies, anesthesia</li> <li>• Peer relationships become important - difficulty being away from friend /school</li> </ul>	<ul style="list-style-type: none"> <li>• Seek control (especially what to do when - may refuse to participate in certain activities like doing chores, homework, etc)</li> <li>• May start asking more questions to gain understanding of transplant and hospitalization</li> </ul>
Adolescent (13-17yrs)	<ul style="list-style-type: none"> <li>• Difficulty being away from friends, school routine</li> <li>• Difficulty with physical appearance (scarring, swelling, etc)</li> <li>• Feelings of hopelessness as they begin to understand lifelong commitment to medications and healthcare                             <ul style="list-style-type: none"> <li>◦ May lead to anxiety or depression</li> </ul> </li> <li>• May express feelings of guilt about having received a transplant</li> </ul>	<ul style="list-style-type: none"> <li>• Non-adherence</li> <li>• Risk taking behaviors</li> <li>• Resist caregiver involvement in medical care</li> </ul>
Young adult (18+yrs)	<ul style="list-style-type: none"> <li>• Difficulty being away from friends, school routine</li> <li>• Difficulty with physical appearance (scarring, swelling, etc)</li> <li>• Feelings of hopelessness as they begin to understand lifelong commitment to medications and healthcare                             <ul style="list-style-type: none"> <li>◦ May lead to anxiety or depression</li> </ul> </li> <li>• May express feelings of guilt about having received a transplant</li> <li>• Navigating transition to independence in care</li> </ul>	<ul style="list-style-type: none"> <li>• Non-adherence</li> <li>• Risk taking behaviors</li> <li>• Resist caregiver involvement in medical care</li> </ul>



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## Typical Emotional and Behavioral Reactions to Transplant by Developmental Level

Long term, children who have undergone transplantation are at higher risk for emotional difficulties (such as anxiety and depression), behavioral difficulties (such as tantrums and risk-taking behavior), attention difficulties (such as ADHD and processing challenges), and learning and academic problems. It will be important to monitor for changes as your child ages and reach out to the transplant team should new concerns arise. Look for any significant changes in your child's emotional, behavioral, social, or academic functioning.

If you have other children, it will be helpful to think about how to foster their positive adjustment post-transplant as well. It is common for siblings to experience a range of emotional responses (e.g., loneliness, jealousy, fear, guilt) both during the transplant process and upon your return home. It can be helpful to spend some special one-on-one time with siblings upon your return, and to encourage sibling and family relationships. Here are some ideas for ways to encourage positive adjustment for the whole family:

- Have your child talk with the family about their experience in Pittsburgh and show pictures from their stay. Some kids have even taken pictures of a stuffed animal in all of their favorite places in Pittsburgh to create a fun way to share their favorite places with people at home.
- Have siblings keep a journal or photo diary of their time while you were away to share upon your return
- Once you return home, institute a family movie or game night to encourage the whole family to spend time together
- As caregivers, make time to process your own thoughts and emotions about the transplant process. This can be done informally through journaling or scrapbooking or utilizing more formal supports such as therapy or counseling.

Adjusting to life post-transplant will take time and effort, but remember your psychosocial team is here to help!



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