

LIVING NOW

Special Issue: **For Parents**

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CARING FOR YOUR CHILD AND FAMILY •

- Adjust to life after transplant
- Help your child express feelings
- Accept help from others

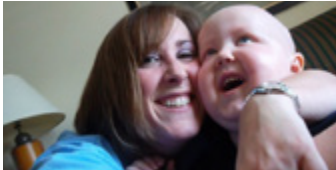
Kyle, transplant recipient,
with his parents and sister



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Kyle, transplant recipient, with his parents and sister

Caring for your child and family

Returning home after your child's transplant is an important milestone. But there is still much ahead in the recovery process.

This special issue includes tips and information to:

- Help your child take medicines and follow the doctors orders
- Give your child opportunities to express feelings and learn when to get emotional support
- Prepare your child for going back to school
- Keep other family members, including siblings and your spouse or partner, connected and feeling supported

In this issue, families share their experiences, challenges, and strategies for managing life after transplant. Think about your own situation and your child as you read others' stories. What works for you and your family depends on a number of things, including your child's age, your parenting style, and your family.

Social workers, child life specialists, and other medical professionals also offer age-specific strategies and tips. As you read through this issue, look for information that relates to your child's age and see if it may work for you.

Adjusting to life after transplant



Kyle, transplant recipient,
with his sister, Lily

As your child recovers, you may wonder how they're adjusting to life after transplant. Children grow and develop at different rates, but there are milestones most children reach within certain age ranges. Reaching these milestones is one sign your child is adjusting well.

The box on page 5 shares some developmental milestones you can watch for based on your child's age. If you have concerns about your child's development and adjustment, talk to your transplant team.

For more information on emotional adjustment after transplant, see page 13.

My biggest life lesson was to just follow the kids' lead, not mine. Their strength and hope are contagious and definitely what keeps me going.

—Diane, mother of Alex and Matt, transplant recipients

Adjusting to life after transplant (continued)



David Jr., transplant recipient, with his parents and sister

For tips on how to care for yourself after your child's transplant, read pages 3-8 from the *Living Now* Special Issue for Caregivers.



QUESTIONS TO ASK YOURSELF

- What can we do as a family to support our child's recovery?
- What can I do to help my child adapt to challenges in a healthy way?

AGE-SPECIFIC DEVELOPMENTAL STAGES AND **WAYS TO SUPPORT YOUR CHILD***

Families who adjust well show love, support and have a sense of humor. They invent a new life together. They focus on the good parts of life, celebrate small victories and don't let illness define them."

—Julie Luke, pediatric nurse practitioner, Methodist Children's Hospital, San Antonio, Texas



RESOURCES FOR PARENT CAREGIVERS

If you need to talk, Be The Match BMT Patient Navigators are available to listen, answer questions and find resources.

Call 1 (888) 999-6743 or email patientinfo@nmdp.org.

Be The Match offers free resources for parent caregivers, with tips and tools to help you.

Visit [BeTheMatch.org/caregiver](https://www.BeTheMatch.org/caregiver) and click on *Support for parents*.

BMT InfoNet and nbmtLINK provide webcasts for parents. Find them at [BMTInfoNet.org](https://www.BMTInfoNet.org) and [nbmtLINK.org](https://www.nbmtLINK.org).

| AGE | CHILDREN ARE | WAYS TO SUPPORT YOUR CHILD |
|---------------------------|---|--|
| Birth to 12 months | Learning about their world and developing a sense of trust | <ul style="list-style-type: none"> • Be with your baby as much as possible. • Continue familiar routines for meals, bedtime and bath time, like rocking, snuggling and singing. |
| 1-2 years | Developing a sense of personal control and independence | <ul style="list-style-type: none"> • Be with your toddler as much as possible; have familiar people care for them. • Let your toddler make choices when practical or possible. • Let your toddler play and be in charge of the game or activity. • Support your toddler with toilet training, feeding and dressing themselves. |
| 3-5 years | Learning more words to communicate what they think and feel. Asserting control over their environment. | <ul style="list-style-type: none"> • Tell your preschooler what will happen before doing a new activity. • Give praise when your preschooler does things independently. • Use play to help your preschooler express feelings. • Remind your preschooler that they did nothing wrong; they didn't cause their disease. |
| 6-12 years | Managing social and school demands. Learning cause and effect. | <ul style="list-style-type: none"> • Give your child choices when practical or possible. • Let your child practice things that are new. • Play games, encourage play and do activities. • Help your child stay in touch with their friends through cards, email, phone calls or letters. |
| 13-18 years | Developing sense of self and personal identity. Striving to be independent from the adults around them. | <ul style="list-style-type: none"> • Answer your teen's questions honestly. • Give time to talk about physical and emotional changes. • Include your teen when talking with the transplant team. • Offer your teen private time. |

*Source: Children's Oncology Group Family Handbook, Second Edition. 2011.

Use creativity and flexibility to **help your child** follow doctor's orders

Once your child comes home after transplant, there are many guidelines to follow to help them stay as healthy as possible. Getting your child to follow those guidelines isn't always easy. Depending on your child's age, you may face different challenges.

The following tips from other families may help you find what works for your child.

Taking medicines

Ben was just 3 years old when he had a transplant. That made it hard for him to understand why he needed to take his medicines. His family used several different tactics to help him take his pills.

For example, it's not easy for a 3-year-old to swallow pills. So, Ben's mom put the pills in ice cream and taught him how to swallow it without searching for the pills.

"He was hesitant at first, but after a while we figured out the right amount of ice cream he could handle without noticing the pills," says Megan, Ben's aunt.

They also enlisted the help of a family friend who was a nurse. When Ben wouldn't take his medicine, they called her and she pretended to be "The Pill Police."

"She would run through a funny routine saying things like, 'Excuse me sir, but I just got a phone call from your concerned grandmother saying you wouldn't take your pills. Is this true?'" Megan says. "She'd tell him that it was important to take pills and stay healthy."



Ben, transplant recipient, with his mom, Katy.

"In the end, Ben would laugh and take his pills."

Lizette's daughter, Amanda, had just turned 15 when she had her transplant for sickle cell disease. "For the most part, Amanda understood why she needed to take her medicines and was good about doing so," Lizette says.

But, there was one medicine she didn't want to take that helped control seizures she developed as a result of chemotherapy. Her doctor asked her to take it for at least a year, which she did. But when her doctor told her she needed to keep taking it after that year, Amanda resisted.

"We tried everything. What finally worked is when we explained the consequences of her not taking the medicine," Lizette says. "She was old

enough to get her driver's permit, but we explained that it would be dangerous to her and to others if she drove and wasn't taking her medicine. Once she could show us she was committed to taking the medicine, we arranged for her to start driving classes."

See the tips on page 8 for more ideas on helping your child take his or her medicine.

Eating foods

What your child can eat and how food should be prepared may be different for you based on your child's health and guidelines from your transplant team. Talk with your transplant team about food choices and food preparation to help your child stay healthy after transplant.

When it came to food choices, Amanda had always been a picky eater. That made getting the right nutrition after transplant especially challenging. Lizette and her husband came up with a creative solution to help.

“We knew that she would only eat half of whatever portion we put in front of her. So, we would double the portions we gave her. For example, if we were making scrambled eggs, we would make sure we made 2 eggs instead of 1. That way, we knew she was getting enough protein,” Lizette shares.

Avoiding infection

For the first few months after transplant, Amanda saw very few people other than her parents and tutor for school. “We really limited the people who were coming to visit Amanda because we wanted to lower the chance of her getting an infection as much as we could. She understood, but not having interaction with her peers was really hard on her,” Lizette says.

Amanda also missed being able to go shopping with her friends at the mall. So, Lizette came up with a solution.

“The mall was too crowded, but Amanda also loved stationery—paper, pens and highlighters were all her thing. We took her to an office supply store since we knew there would be fewer people there,” Lizette says. “She walked in, wearing her mask of course, breathed in and said, ‘I love that smell of new stationery!’ It was a good way for us to get her out of the house in a safe way and help her feel normal.”

When Amanda was able to go back to school, she still needed to wear her mask. “She didn’t like the idea, but she understood why it was important so she did it. Her friends



Amanda, transplant recipient, with her mom, Lizette

supported her by wearing masks too so she wouldn’t feel uncomfortable. They’d even do it when they would go to the mall,” Lizette says.

Ben’s family scheduled two car rides a day so he could get out of the house. They would take his tricycle with them and found parks and other public places where he could walk, ride and run.

“He had to wear his mask outside of the house, but once he was in the car or outside in a park, he was allowed to take off his mask as long as there were not a lot of people around or dust blowing,” Megan says.

They also found fun ways to get Ben to wash his hands.

Megan says, “We bought Ben travel size kids’ antibacterial gel that he carried in his backpack and used after touching anything. It made him laugh and gave him some control over his routine”.

Find what works for your child

While these creative solutions worked for Ben, Amanda and their families, every child and teenager is different. You may need to try a variety of techniques to find something that works.

Your transplant team is available to help you. Ask if they have any creative ideas that other families have used.

If you have trouble getting your child to take medicines or follow any guidelines, talk with your transplant team right away for help.



MY CHILD CAN’T TAKE THE MEDICINES. **WHAT SHOULD I DO?**

Explain to your child it’s not their fault, and you’re there to help.

Transplant and its side effects can cause an upset stomach or nausea, and your child’s stomach may not be used to food, let alone medicine.

Call your transplant team for suggestions. You may be able to change medicine brands, the dosage or the timing of when medicines are given.

If your child vomits or refuses to take the medicine, your transplant team can tell you when to give the medicine again and when to come in to the clinic or hospital.

Ideas to help your child **take medicines:**

| AGE | SITUATION | TIPS |
|----------------|---|---|
| Under 2 | Babies and toddlers under age 2 can't understand why medicine is important. But they find comfort in routine. | <ul style="list-style-type: none"> • Slowly squirt liquid medicine into the side of their mouth. • Put the medicine into a nipple and allow your child to suck on the nipple. |
| 2-4 | Toddlers understand simple explanations for taking medicines, such as "the medicine will help you feel better." But, they may not like the taste or know how to swallow medicine. | <ul style="list-style-type: none"> • Mix medicine with applesauce, juice, pudding or ice cream. • Avoid distractions. Turn off the TV or take a break from playing so your child can focus on taking medicine. • Include taking medicines in their play. Your child may want to give pretend medicine to a stuffed animal or doll before taking the real medicine. |
| 5-8 | Children in this age group appreciate having some control and enjoy tracking progress to earn rewards. | <ul style="list-style-type: none"> • Talk with your child about the importance of taking medicines to get better and stay healthy. • Offer your child a choice of time and place to take the medicine, such as now or in 5 minutes. Give your child choices about what to drink or eat with it. • Use a sticker chart to track medicine and offer a small reward for milestones. |
| 9-12 | Older children may be more aware of side effects caused by each medicine. They also understand the consequences of not taking their medicines, such as having to go back to the hospital. | <ul style="list-style-type: none"> • Involve your child in their health care. If your child has questions about the medicines or concerns about side effects, help them write down questions to ask the doctor at the next appointment. • Schedule medicines around times your child can do something fun. For example, after you take your medicine, you can watch this video or TV show, or do this activity. |
| 13-18 | Teens may rely on parents for support but also want to gain independence. Fitting in with their peer group is important to teens. They may be resistant to taking medicines or doing things that make them feel different. Some teens may hide medicines or secretly spit them out. | <ul style="list-style-type: none"> • Stress the importance of taking medicine and the consequences of not taking it. • Send a text message with a reminder to take the medicine, or set a reminder on your teen's cell phone. • Reinforce desired behaviors. Notice when your teen is being responsible for their care and offer a compliment. • As needed, supervise your teen taking medicines to make sure they're not being skipped or discarded. |



RESOURCES FOR YOU

Sometimes it can help to talk to another parent caring for a child after transplant. Our Be The Match *Peer Connect* program connects you with a trained volunteer who is also a parent caregiver. They can answer your questions and share their own experiences. Learn more and request a connection at [BeTheMatch.org/peerconnect](https://www.BeTheMatch.org/peerconnect).

Use the Be The Match free After Transplant Care Guide mobile app to help plan for doctor appointments and set reminders. Visit [BeTheMatch.org/careguide](https://www.BeTheMatch.org/careguide).

Find tips to help your teen be more involved in their health care at [GotTransition.org](https://www.GotTransition.org).

It's back to school time



Carol, transplant recipient

Going back to school is an important part of your child's recovery. But this happens at different times for different children. Depending on the type of transplant and how recovery goes, a child may go back to school within several months of transplant. Other children may go back to school a year or more after transplant. Your child may work with a teacher or tutor to keep up with school work before returning to the classroom.

You can help prepare your child, teachers and classmates to make the return to school, whenever it happens, a little smoother.

Prepare the school for your child

Before your child goes back to school:

- Ask your transplant doctor, psychologist, or social worker to write a letter to explain your child's situation and request special accommodations from the school system. Send copies of the letter to the principal, teachers and school nurse.
- Meet with teachers, school nurses and school staff (like the principal or guidance counselor). Talk to them about the medicines your child is on and how it may impact their mood or behavior. Plan what to do if issues come up during the school day.
- Talk to the school about any special accommodations your child may need. Accommodations can include:
 - More time to finish assignments or take tests
 - Being able to use calculators and recorders
 - Completing assignments in a different way. For example, if your child has a hard time writing, ask if they can provide verbal answers.
 - Being allowed more bathroom breaks
- See the section on "Your child's education rights" on page 10 for more information about receiving special services at school.



Prepare your child for school

You and your child may experience many emotions as your child returns to the classroom. Your child may feel excited, hesitant and self-conscious. Classmates may not know what to say and will likely have questions.

Before the first day back to school, coordinate with your child's teacher a time to visit the classroom to help with your child's transition back to school. This may include a time to talk about the BMT process and answer questions.

You can also help prepare your child for how to answer questions. Some children and teens like to use a straightforward approach, like, "I was in the hospital and had a transplant to treat my disease. Now the disease is gone. I still wear a mask and take medicine to protect me from germs that could make me sick."

Depending on your child's age and personality, they may want to answer these questions or have a teacher or others from the school do this. The best thing you can do is talk with your child and come up with a plan they're comfortable with.

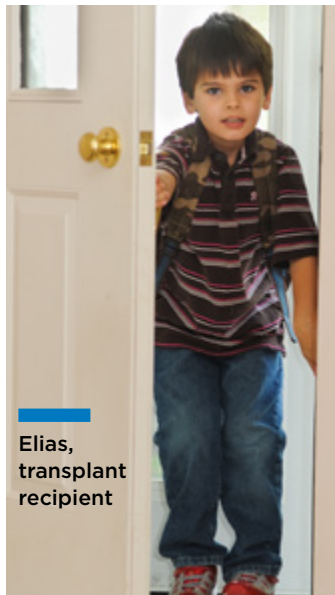
Tips to help your child adjust

After being away from school and friends for so long, your child might feel lonely or isolated. Here are some tips to help your child reconnect with classmates:

- In elementary school, talk to other parents and arrange for your child to spend time with friends. Let other parents know your child isn't too sick to play with other healthy, vaccinated kids.
- In junior high school, a child's focus is often on identifying with a peer group. Ask the school to help your child participate in activities in and out of the classroom as safely as possible.
- In high school, your teen may want to connect with peers, but also find their own unique identity. Support your teen by encouraging safe choices and healthy connections.

Remember to check in with your child to see how they're adjusting. Maybe it's talking during dinner or a car ride, or asking them to "rate your day." Check in with your child's teachers and counselors, too.

The Be The Match® *Patient Support Center* can help you find resources to help with the transition back to school. Contact our BMT Patient Navigators at patientinfo@nmdp.org or 1 (888) 999-6743.



IF YOUR CHILD DOES NOT WANT TO GO TO SCHOOL

There are many reasons a child or teen may not want to go to school. Talk to your child and try to find out what's going on. Knowing the cause will help you find a solution.

For example, if your child has trouble concentrating or lacks energy to get through the school day, talk to the school about easing back into the routine. You may want to try shorter days or home tutoring for a while.

If bullying is happening, talk to the teachers and principal right away for help stopping the bullying behavior. Remember, you're your child's advocate. Insist on what's best for your child.



YOUR CHILD'S EDUCATION RIGHTS

After transplant, your child may need special services at school. For children in K-12, these special services are typically part of an Individual Education Program (IEP) or 504 Plan.

Individual Education Program (IEP):

- A legal document that explains your child's needs, the special services the school will provide and how the school will measure your child's progress.
- Requires an evaluation by a professional, like a school psychologist to see if your child qualifies for special services.
- Handled the same way in every school district

504 Plan:

- A document that explains services your child will receive, but it's not as detailed as the IEP.
- Requires an evaluation by a professional, like a school psychologist, to see if your child qualifies for special services. The school can gather information from many sources, like what you and your child's teachers have observed, a doctor's diagnosis and the results of an IEP evaluation, if one was done.
- Can be handled differently by each school district

If your child qualifies for either an IEP or a 504 Plan, you'll work with school staff to make a plan for your child.

Talk to your child's teacher or school staff to learn more about IEPs and 504 Plans and to schedule an evaluation. Ask your transplant center social worker for help getting any required documents.

To learn more about special education services, go to ed.gov/parents.



Ashley, transplant recipient

There are many reasons a child may struggle with the transition back to school. It can be hard to separate from parents who have been present throughout their treatment. They may look different, feel different and worry about getting school work done. If your child is struggling, talk to them about their feelings - don't assume you know what is wrong. As you provide support to your child, take care of yourself—the school transition is difficult for parents too.

— Katie Schoeppner, MSW, LICSW,
Supervisor, Counseling Services,
Be The Match Patient Support Center

QUESTIONS TO ASK YOURSELF

- How can I help prepare my child to go back to school?
- What can I do to help the school be ready?
- How am I encouraging my child to connect with friends?
- How does my child prefer to communicate with others about the transplant experience?
- How do I plan to check in with my child daily?

WHEN YOUR CHILD IS GOING BACK TO COLLEGE

Your child may or may not be ready to take on a full class load when going back to college. Reassure them that's okay. They may need to ease back into things just like people who are going back to work.

Before starting the next college semester, encourage your child to:

- Meet with the school's disabilities office or academic services to learn about the resources available.
- Meet with a professor in their area of interest or major and ask for their support. They may be able to give advice and be your child's advocate if needed.
- Talk with each professor before classes start or soon after. Work with the professors to set reasonable accommodations for completing assignments.



RESOURCES FOR YOU

Get more tips for helping your child return to school. Go to the *Transplant for Children and Teens* section of [BeTheMatch.org/patient](https://www.bethematch.org/patient). Then, go to *Going back to school*.

The American Childhood Cancer Organization offers a booklet for parents and teachers called *Educating the Child with Cancer: A Guide for Parents and Teachers*. Find it at [acco.org](https://www.acco.org).

LD Online offers resources for parents wanting to learn more about the IEP process. Find these at [ldonline.org/indepth/iep](https://www.ldonline.org/indepth/iep).

For tips on how to address bullying, go to [stopbullying.gov](https://www.stopbullying.gov) or [pacer.org/bullying](https://www.pacer.org/bullying).

The National Children's Cancer Society offers educational resources, including the Beyond the Cure Ambassador Scholarship program. The program provides college scholarships to childhood cancer survivors. Find more information at [thencs.org](https://www.thencs.org).

Give your child the tools to express feelings



Dalton, transplant recipient



When should I seek additional help?

You know your child best. If your child is sad, worried, afraid or irritable on most days for 2 weeks or longer, it could be depression or anxiety.

Depression and anxiety can be treated. Your child's doctor can help you learn about resources and getting the help your child needs. If you have any concerns about how your child is coping, talk to your transplant team.



RESOURCES FOR YOU

CancerCare provides support and resources for children and teens related to coping with cancer. Go to [CancerCare.org/children](https://www.cancercares.org/children).

Leaving the hospital after transplant is a milestone in your child’s treatment and can come with many emotions.

While your child may expect to feel well right away, it may be months or longer before he or she can be fully active in everyday activities.

During this time, it’s important to be aware of your child’s emotions and to provide them opportunities to express feelings—whether through words, music, art or another way.

Things you can do

- Provide opportunities for your child to talk and share feelings. For example, when your child is upset, ask them to share how they feel. Let them know you’re listening and eager to help. Answer questions honestly to help your child know what to expect. If your child isn’t ready to talk, it’s okay. They just might not know how to express their feelings, or may be sharing through art, music or even the way they’re playing.
- Tell stories of how you’ve felt in similar situations, how you handled it (for good or bad) and how it turned out.
- Come up with options and problem solve together. You may want to try creative ways to express feelings, like drawing pictures, writing a story, acting out a play or singing a song.
- Help your child notice the progress made. Remind your child of the things that are going well in recovery. Help your child notice the good and enjoyable things in life, like a favorite activity or a pet.
- Give comfort by being with your child.
- Focus on routine. Help your child know what to expect. Talk about the plan for the day and establish a schedule for day-to-day activities.
- Give choices. Encourage your child to participate in decision-making in daily activities, and planning special outings, vacations or celebrations.
- Express affection and encouragement. Say the words, “I love you,” “I am proud of you,” and “I am here for you.”
- Hold your child, give hugs, or offer a hand massage or back rub.

Don’t forget, you’re not in this alone. Talk with your child’s health care team for ideas on how to help your child learn healthy ways to cope with emotions.

Tips to help your child adjust

| AGE | TIPS |
|-------|---|
| 0-4 | <ul style="list-style-type: none"> • Hold, rock, provide comfort. • Encourage self-soothing behavior such as snuggling with a favorite blanket or stuffed animal. • Distract your child with play or humor. • Use music, art or active role playing with dolls. • Follow a routine for quiet time, naps, potty training and family meals. These routines become familiar and comforting. • Use words to praise desired behavior. |
| 5-12 | <ul style="list-style-type: none"> • Use arts and crafts like drawing, painting, sculpture, beads, fabric, etc. Visit BeTheMatch.org/supersam for activity sheets. • Make a collage of family, friends and experiences using photos, cut outs and drawings. • Write and illustrate or act out stories and plays. • Make creations with toy building bricks and make up stories about them. • Sing and make up your own songs. • Make up an expressive dance. • Have fun with family and friends using board games, video games, cards, etc. |
| 13-18 | <p>Encourage your teen to:</p> <ul style="list-style-type: none"> • Join a group of people with similar interests. • Try different kinds of physical activity, like walking or gentle yoga. • Spend time with someone they enjoy. • Share feelings through journaling or blogging. • Gain greater independence. Give a compliment when your teenager demonstrates increased maturity and responsibility. • Join a cause or volunteer to help others. |



Support for siblings

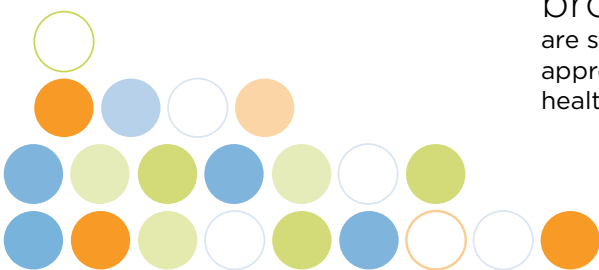
Constance (right), transplant recipient, with her parents and sister

The changes your family experienced going through transplant and recovery can be stressful for everyone, including brothers and sisters. There are signs of stress to watch for and approaches to help them cope with stress in healthy ways.

Signs your child may be feeling stress

Signs of stress for siblings of transplant recipients may include:

- Changes in eating habits
- Trouble sleeping
- Drop in school performance
- Headaches
- Anxiety
- Worry
- Anger



Children show signs of stress differently depending on their age and developmental stage. But, if you notice any of these signs in your child, talk to your child's health care team. They can share resources to help you and your family. You can also use the tips listed here.

Provide some routine

Children find comfort in routines. Here are some ways to help keep routines going:

- Prioritize family time. Make special time to check-in.
- As much as you can, pick something that will be the same every day. For example, keep breakfast or dinner at a set time.
- Tell your children about upcoming changes. Make a family calendar so everyone knows what's coming next.
- Arrange for your children to participate in school activities and spend time with friends.

If your focus needs to be on your child's transplant recovery, ask other family members and friends for help supporting your other children. Tools like [ShareTheCare.org](https://www.sharethecare.org) and [LotsaHelpingHands.com](https://www.lotsahelpinghands.com) can help you organize help from family and friends.

Help children express their feelings

Not all children are affected by stress in the same way. It's normal for siblings to have many different feelings. Common feelings include:

- Loneliness
- Sadness
- Anxiety
- Jealousy
- Guilt
- Fear

You can help your children identify and express their feelings, and manage their emotions in a healthy way.

Here are some tips. Use those that are most appropriate for your children's ages and developmental stages:

- Talk openly and honestly about difficult topics.
- Have your children draw pictures of how they feel. Then, ask them to talk about what they drew.
- Ask your children to finish the sentences, "I am worried about _____." "You can help me feel better by _____."
- Use dolls or action figures to have your children act out their feelings.
- Give your children a journal where they can write down their thoughts and experiences.
- Listen and provide reassurance.
- Encourage your children to ask questions. Give as much information as they are able to understand based on their age and developmental stage.
- It's okay to say, "This is new for me too," and that you'll work together to keep figuring it out.

The transplant experience can lead to positive experiences for siblings, too.

Your children might be more sensitive to others' feelings or have more coping skills.

Show your children your support for them

Throughout your child's transplant journey, you can support siblings by showing and telling them they are loved and you are there for them, too.

These ideas might help:

- Take time each day to ask about their day, activities and friends.
- Celebrate the accomplishments in their lives.
- Ask a family member or friend to spend quality time with your children when you can't.
- Encourage family and friends to include all of your children in their visits and well-wishes.
- Tell each child the special things you love about them.
- Hug your children and say the words, "I love you."

Your transplant center's social worker or child-life specialist can also provide ideas and support.

QUESTIONS FOR YOU

- What can you do to spend quality time with each of your children?
- Who could you ask to help keep routines going at home?
- How are your children showing their special roles in your family?



RESOURCES FOR SIBLINGS

Alex's Lemonade Stand offers support and age-specific resources for siblings of children with cancer. Learn more at [AlexsLemonadeStand.org/supersibs](https://www.AlexsLemonadeStand.org/supersibs).

Be The Match offers activity sheets for siblings of children who had a transplant. Find them at [BeTheMatch.org/supersam](https://www.BeTheMatch.org/supersam) and select *Super Sam versus the Marrow Monsters*.

It's so important to take time for yourself

As told by Ann, Caleb's mom

When he was 19 months old, doctors diagnosed Caleb with a very serious autoimmune disorder called familial hemophagocytic lymphohistiocytosis (FHLH). He had a transplant just before he turned 2. His transplant and recovery turned life upside down for Caleb's family.

Here, Caleb's mom, Ann, shares their family's experience after transplant and offers advice for other parents.

As Caleb recovered from his transplant, there were definitely some struggles. Some of the tips we got for helping him adjust worked great, others—not so much.

Caleb was so little he didn't know why he had to take his medicines. He'd fight us, and we would have to hold him down so we could squirt them in the back of his mouth. It was hard to do, but we got them in him. As he got older, we tried flavored meds, but he still hated them. Eventually, we found chocolate syrup cut the bitterness of the cyclosporine.

Then there was the mask. He HATED wearing it. We tried decorating it, but he didn't care. We all wore masks, and he still didn't care. So, we just stuck to consequences. When we went out, he HAD to wear the mask. If he refused, he just couldn't go. It was as simple as that.

We tried not to fight about it, or get mad, it was just a fact. And eventually, he would give in.

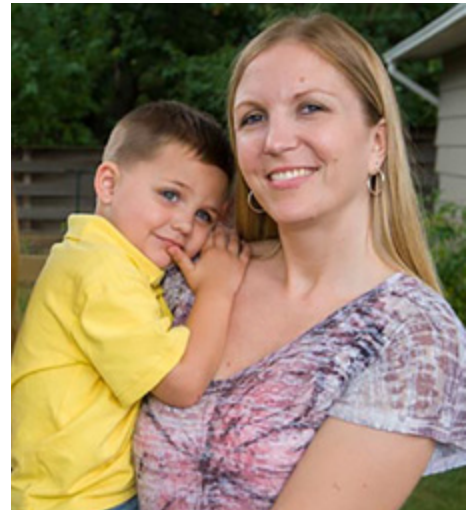
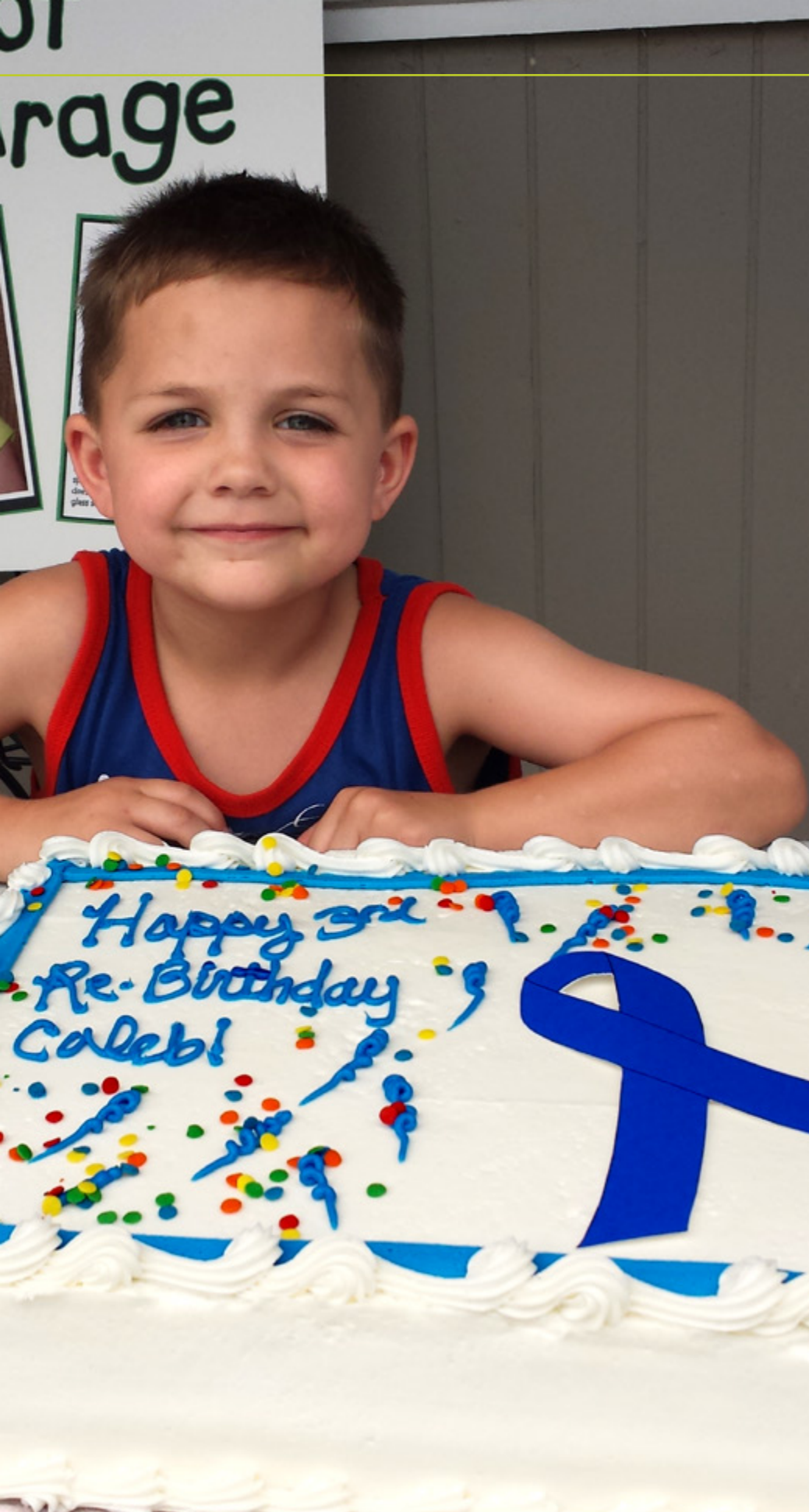
When he wasn't healthy enough to go outside, he would sometimes cry at the window because he wanted to play in the yard with his sister, Hannah, who was 5 at the time. So, we made an indoor backyard in the basement. We included an outdoor scene with birds, rabbits and fish painted on the walls, and a fuzzy green blanket for grass.

The transplant was hard on Hannah, too. She needed mom and dad, and we made a point of doing special things with just her. One project she especially enjoyed was painting rocks—worry stones—one for each member of our family.

Looking back, I wish I would have accepted more help. At the time, I was so focused on what I had to do, I wasn't good at letting other people get involved. And frankly, I was terrified at the thought of leaving Caleb with anyone overnight. But it's so important to take time to yourself, to take care of yourself or go out on a date night. It helped so much to get away for a few hours.

Today, Caleb is fantastic. He's healthy, active and has a bit of a mischievous streak—but after what he's been through, even that is a good thing! And as for me, I returned to work as a health unit coordinator for a home health care company, and I love it!





Caleb, transplant recipient, with his mom, Ann



YOUR SENSE OF COMMUNITY

Being a parent can bring you joy as well as challenges, especially when your child is ill. No one can do it all alone. Think about your needs and your support community and ask yourself:

- Who has offered to support me and my child?
- What tasks do I have, and who can I ask for help?
- When can I schedule 15 minutes for myself?
- What activities help me relax and recharge?

Empowering our teen helped prepare her for transplant and recovery

As told by Kathy, Lizzie's mom

Kathy's daughter, Lizzie, was born with Diamond-Blackfan anemia, a rare disease where the body isn't able to make red blood cells.

This meant frequent visits to the hospital and clinic for treatment. As Lizzie got older, her body started having problems. With the support and guidance of her family and health care team, Lizzie made the difficult decision at age 18 to get a transplant—the only cure for Diamond-Blackfan anemia.

Along with building a strong support system of family, friends and health care providers, Kathy found that involving her daughter in health care decisions made all the difference.

“Lizzie’s world included health care right from the get-go. It was fortunate I worked in health care and was as ‘comfortable’ as someone could be navigating the system for a child with a chronic illness.

From the time she was a little girl, I taught Lizzie what she would need to understand her world, like how to manage taking her medicines. It put the power in her hands and helped her become a true partner in her health care as she grew older.

It helped prepare her for what was to come.

As a teenager, her body started having trouble due to her life-long treatments. We had a decision to make. Should she get a transplant or not? Ultimately, because she was 18, it was her decision.

Lizzie interviewed her transplant team and did her research with the help of her older sister. We had many conversations as a family. She knew what the results and challenges could be. She decided it was time for transplant. And, it was time for us to make a plan.

In the first few weeks after transplant, our plan was for either my husband or me to be constantly by Lizzie’s side. We were updating family and friends, reviewing her lab results with her doctors, and doing what we could to find foods and drinks that her changing taste buds could tolerate.

It surprised us how difficult that was. Everything tasted terrible at first. We would come back from the store with bags of drinks, snacks and food just trying to find something since we knew how important nutrition is after transplant.

We live in Arizona and Lizzie’s transplant team was in Minnesota, so that was a challenge, too. We were fortunate to be able to plan for her older brother and sister, family and friends to make the trip and spend time with Lizzie. This gave my husband and me time to step away and recharge.

Throughout those early months after transplant, being able to spend time with her friends was a BIG deal. And her friends were amazing. We scheduled times for them to come and be with her so she was never alone. After a while, her friends knew what to do and how to help her. So by noon most days my job was done. Her friends took over, and I managed the big stuff.

The balancing act wasn’t easy. But we developed a system that worked for all of us. Today, I’m happy to say Lizzie is doing well and looking forward to all life has in store for her.”



Lizzie, transplant recipient

YOUR TEEN'S SENSE OF INDEPENDENCE

Your teen is developing a sense of self and personal identity. While they're striving to be independent from the adults around them, your teen still needs support. Think about your teen's sense of independence, and ask yourself:

- In what ways has my teen become more responsible?
- How can I involve my teen in health care decisions?

THE LIVING NOW SERIES

Each issue in the Living Now series addresses different aspects of life after transplant—from 3 months after transplant to 2 years and beyond. Each person's experience is different. The articles in the magazine are not a timeline to measure yourself or your child against. They are a collection of observations, tips and resources designed to help make the most of life after transplant.

This newsletter is produced by Be The Match® *Patient Support Center*. The information is based on input from blood and marrow transplant experts and represents general principles and recommendations. It is not intended to replace, and should not replace, a doctor's medical judgment or advice. Always consult with your child's medical team regarding your specific situation.

Be The Match offers many free programs and resources to support patients, caregivers and family members before, during and after transplant. Connect with us in the way that works best for you.

ONLINE: [BeTheMatch.org/ParentCaregiver](https://www.BeTheMatch.org/ParentCaregiver)

REQUEST INFORMATION: [BeTheMatch.org/request](https://www.BeTheMatch.org/request)

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Support for parents at every step



Jade (right), transplant recipient, with her parents and brother

The Be The Match® *Patient Support Center* is here to support you as you care for your child after transplant. We offer many free resources to help you take care of your health, so you can be there to support your child.

Our BMT Patient Navigators offer one-on-one professional guidance and education by:

- Answering your questions
- Sharing resources
- Providing support

Want to talk with someone who's been there? The Be The Match *Peer Connect* program connects parents of younger patients with other parents who have gone through the transplant process with their child. Support and guidance is provided over the phone or by email.

No question is too big or too small. If we don't have what you need, we'll help you find someone who does.

- **Call:** 1 (888) 999-6743
- **Get Support:** [BeTheMatch.org/one-on-one](https://www.bethematch.org/one-on-one)
- **Connect:** [BeTheMatch.org/PeerConnect](https://www.bethematch.org/PeerConnect)
- **Email:** patientinfo@nmdp.org

Every individual's medical situation, transplant experience, and recovery is unique. You should always consult with your own transplant team or family doctor regarding your situation. This information is not intended to replace, and should not replace, a doctor's medical judgment or advice.

About Be The Match®

For people with life-threatening blood cancers—like leukemia and lymphoma—or other diseases, a cure exists. Be The Match connects patients with their donor match for a life-saving blood or marrow transplant. People can be someone's cure as a member of the Be The Match Registry® financial contributor or volunteer. Be The Match provides patients and their families one-on-one support, education, and guidance before, during and after transplant.

Be The Match is operated by the National Marrow Donor Program® (NMDP), a nonprofit organization that matches patients with donors, educates health care professionals and conducts research so more lives can be saved.

Learn more at [BeTheMatch.org/patient](https://www.bethematch.org/patient) or call 1 (888) 999-6743.

