

The Parent's Companion to
Communication:

Developing skills for
**effective
communication**



Ashley (transplant recipient) with her parents, Deb and Terry



What to **say**— Finding the words

Throughout your child's transplant journey, being able to communicate simply and directly — while avoiding misunderstandings — is critical for everyone involved. There are many people you need to communicate with:

- Your child's health care team
- Your child going through transplant
- Your partner, children, and other family members who need to stay informed
- Friends and loved ones who want to help

With so many people involved, communication can be complicated. This chapter will provide some useful tips on how to communicate with all of those involved in your child's care and those providing support to you and your family.



Rocky, dad of Elias, age 1 at transplant

The purpose of *The Parent's Companion to Communication* is to help you develop and use more effective ways to communicate. In this chapter:

It's not what you say, it's how you say it

- Be clear — and get what you want
 - Choose the best words to get the best results
 - Consider your child's developmental stage when communicating
-

Family matters

- Keeping each parent informed when apart
 - Talking with family and friends
 - Staying connected with your other children
-

Be situation savvy

- Help your health care team help you
- Help your child communicate with you and the health care team

“It was difficult to get family members to understand the boundaries of his transplant and treatment plan. His grandparents had a hard time understanding that they couldn't just come up to the hospital and see him — that any cough, sneeze, or runny nose could be dangerous. My husband and I updated them almost daily and let them know TJ knew they were thinking about him.” — **Sherri, TJ's mom**

How are you doing **right now**?

Before you read on, take a minute to answer a few questions about your current communication skills.

Do you find it easy to find the right words to explain what you need? Yes No

Have you and your partner talked about how to keep each other informed when apart? Yes No

Do you feel comfortable talking with your friends and family?..... Yes No

Do you feel like you've stayed connected with your well children? Yes No

Do you know how to help your child talk to the health care team?..... Yes No

Do you have a notebook to keep you organized? Yes No

If you've checked "No" more times than "Yes," you're not alone. This chapter will provide some tips that may prove helpful and make you feel that you are communicating effectively.

It's not **what** you say, it's **how** you say it



Lizette and her daughter,
Amanda, age 15 at transplant

One way to make sure your thoughts are organized before you meet with a doctor is to put down on paper these completed phrases:

What is happening is ...

My concern is ...

What I need is ...

You have a lot of people you need to communicate with. Your child's health care team. Your spouse and children. Your parents, extended family, and friends. With so many people involved, communication can be complicated. And, it's not always easy to find the right words to explain what you need from others.

In this first section, you'll learn how to avoid misunderstanding and conflict by applying some general, common-sense communication skills that will raise the odds of successfully communicating.

Be clear — and get what you want

One place to start for good communication is to figure out what it is that you need before you start talking with others. When we're not clear with others about what we really need or want, it's easy to get frustrated, especially when others don't respond in the way we hope they will.

When people talk, they generally want 1 of 4 things from the person they are communicating with: information, understanding, advice, or reassurance.

By taking time to think about what it is you want to get across, you're likely to say what you need more clearly. For example, let's say your child has been having a hard time keeping a new medication down and you are concerned. Do you need information, advice, understanding, or reassurance? You probably want information in this case, and you can make this explicit in your question to the doctor:

"My child has been having a hard time keeping this medicine down. I'd like to know what we can do to help or if we need to try a different medicine."

Choose the **BEST WORDS** to get the best results

In most situations, it is good to be assertive — that is, making your needs known in a respectful way. You don't want to be too passive, and not let others know what you need. But you also don't want to be so aggressive that others may start avoiding you.

Here are some ways to say things that can help you get the response you want.

Use “I” statements.

Statements that start with “you” can put people on the defensive.

instead of

“Why aren't you doing anything about my child's pain?”

say

“I am concerned that my child is in so much pain. What options are there to help my child be more comfortable?”

Start with a positive instead of a negative.

Nobody likes to be talked to in a negative way, because it feels like an attack.

instead of

“You don't explain things well. We don't know what to expect.”

say

“We appreciate all you have done for us. Can you please give us more information on what we can expect for side effects?”

Describe your feelings, don't display them.

Say what you are feeling without displaying anger, frustration, or fear.

instead of

Raising your voice or pounding your fist on the table

say

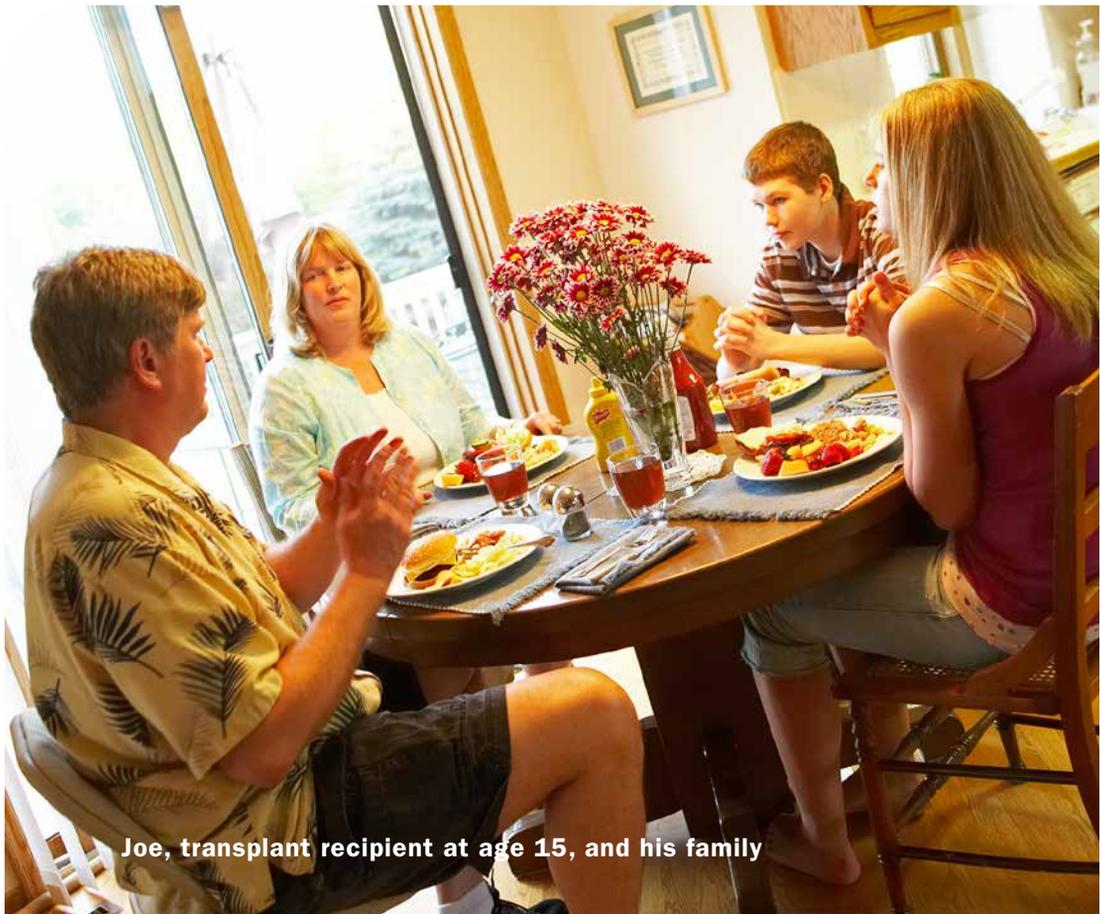
“I feel very angry and frustrated that we have been waiting so long.”

“We weren't shy and we were relentless. Our (health care) team appreciated the fact that parents know their child best, and that there is great value to that.” — **Tracy, Cameron's mom**

Family matters

Sometimes it can be hard to find the “right” words to help your child and other family members. There is likely not one way to communicate that will work for everyone in your family. How much they want to know or talk about will be different depending on their age, personality, and developmental stage. One of the most important things you can do is be honest and encourage open communication.

If you aren't sure what to say, it's okay to say so. You can show love, support, and caring for each other by holding hands or just sitting with your child or family member for a while.



Joe, transplant recipient at age 15, and his family

“We had shifts at the hospital with our son, so we kept a journal that stayed at the hospital. Before we left for the day, we would write down how our time was with him. Because our time with each other was limited, it was a great way to ensure that nothing important from that day got overlooked.”

— **Sarah, Alex’s mom**

Keeping each other **in the loop**

Many times when a child is going through transplant, one parent needs to return to work, and may need to be caring for other children at home. For this reason, it’s not unusual for one parent to be more involved with the child’s day-to-day medical care. Or, parents may be separated or divorced, which can also cause challenges in communication.

When one parent can’t be at the hospital or at home as often, it’s important for parents to work together so everyone stays up-to-date. You may want to keep a notebook so you can share information back and forth. Or, consider setting aside time each night to talk about what’s happened that day.

If you’re having trouble staying connected, talk with your transplant center’s social worker. Your social worker may be able to help you find solutions that work for your family.

Talking with family and friends

Family members respond to transplant in many different ways. Some may feel that they need to talk about their feelings, while others may prefer to keep their feelings private. Some may be information-seekers, and others may feel more anxious having too much information.

Understand that there are different coping styles and none is “wrong.” Here are some tips on family communications:

- Have family meetings to talk about things as a group
- For those who are not comfortable in a group, have one-on-one conversations
- Give everyone an opportunity to talk
- Don't set time limits on discussions
- Ask your social worker or child-life specialist for help planning family conversations

“We would talk to a child-life specialist before we talked to our kids. They would help us find a way to explain what we needed to communicate to the kids in terms that were easier to understand.”

— **Sarah, Alex's mom**

You may find that friends and distant family call or email you to ask how your child is doing. This communicates support, but the need to respond to all those calls and emails can feel overwhelming. A great way to keep your friends and family informed is to use technology to help you. Some parents find it helpful to use social media or free websites such as caringbridge.org or carepages.com to post updates. These websites include a patient care journal to post updates to family and friends as well as a guestbook for messages of support from loved ones.

“CaringBridge® was awesome for keeping folks up to date on our journey status. The responses we got from people who were following our journey were very uplifting and got us through many low days.”

— **Lisa, Kameron's mom**



Deb and Terry with their daughters Ashley (transplant recipient) and Brittney

Staying connected with your other children

As one child goes through transplant, brothers and sisters are affected, too. With everything you must do to support your child who is sick, it can be difficult to stay connected with your well children. But, there are things you can do to show your other children that they are important and loved, too.

Here are some ideas that you can try whether or not you're able to see your children every day:

- Take time each day to ask about their day, activities, and friends
- Celebrate the accomplishments in their lives
- Ask family members or friends 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
- Talk openly and honestly about difficult topics
- Tell each child the special things you love about them
- Hug your children and say the words, "I love you"

Tools to help your well children communicate can be found at BeTheMatch.org/patient-supersam. Your transplant center's social worker or child-life specialist can also provide ideas and support.

"We sat down with the other caregivers and made a schedule of who would stay at the hospital and when. Our focus was not only on our child having transplant, but also on our oldest. We wanted to keep her life as routine and normal as possible, and make sure she didn't feel abandoned or left out. I was at the hospital during the day, my husband was there in the evenings, and the grandparents at night. Both of our kids always had family time, and felt loved and cared for."

— **Sarah, Alex's mom**

"One of the hardest things was having to leave our younger son with my brother and sister-in-law while we were away for transplant. We gave him a cell phone, set up Skype, and connected with him every day. The 4 of us still said prayers together every night."

— **Mary Ellen, Louis's mom**

Communicating with your child

As a parent, it can sometimes be hard to know when to encourage your children, and when to just support and protect them. One of the most important things you can do is keep the lines of communication open, and let your child express feelings, whether it is through words or actions. If you're not sure of the best way to talk with your child, talk with your transplant center's social worker for suggestions.

Here are some tips to help you:

don't

- Force your child to talk if your child is not ready
- Tell your child how to feel
- Feel like you must come up with a solution or know all the answers
- Assume that it is your fault if your child is feeling down or depressed
- Feel that you must cheer your child up in order to be helpful
- Try to talk your child out of how he or she is feeling

do

- Let your child express feelings. Use art or music as a way for your child to express those feelings
- Encourage your child to identify causes for the feelings
- Encourage your child to ask questions
- Be honest with your child
- Actively listen and try to understand
- Offer support and encouragement
- Let your child know that the feelings are normal
- Encourage your child to talk to friends and other family members



Jill and her son, Murray

“There were many times when we were unsure how Murray was going to pull through, so we tended to spoil him. Later, when he was feeling better, he could be difficult to discipline, especially while he was on steroids. Our coping mechanism was to give him lots of hugs and love and just hold him.” — Jill, Murray's mom

Parenting and discipline

Disciplining a child who is seriously ill can be difficult for some parents. It can be hard for parents to reinforce rules when they think about all their child has been through. But, children depend on their parents to teach them appropriate behavior. When you clearly communicate your expectations, it can be reassuring to your child, and also help your child communicate more effectively with you and the care team.

Here are some tips that may help you:

- **Understand what causes poor behavior.** Acting out is often a sign of frustration and discomfort. In these situations, your child needs your guidance and support as well as clear limits.
- **Be a positive role model.** Show the behaviors you expect from your child. Talk respectfully, take time outs when you need to, and apologize when you have been wrong.
- **Set clear rules and expectations.** Make sure that the rules are age-appropriate and realistic.

- **Help your child understand and express feelings.** Explain there are ways to deal with your feelings so they don't control your behavior. Help your child understand being hurtful or destructive is not allowed.
- **Develop coping strategies.** Explore acceptable ways for your child to express and release anger and frustration. For example, expressing feelings through words, art, physical activity, or calming exercises.
- **Enforce consequences.** Set age-appropriate consequences that match the severity of the behavior. Time outs can work well for younger children. Loss of privileges might work well with older children.
- **Praise good behavior.** When you see positive behavior, reinforce it with praise and attention.

“We helped Louis understand that while he feels helpless, he is not. He can control how he treats people and what comes out of his mouth. By calmly explaining his needs and concerns, he will be better heard by the doctors.”
— Mary Ellen, Louis’s mom

Be situation savvy

Help your health care team help you

Coordinating your child's care isn't easy, especially when there are many health professionals involved who may have different specialties and might not be at the same location. The more people involved in your child's care, the more likely miscommunication can occur, which can cause additional stress.

There are a lot of simple things you can do to help improve communication.

Don't hesitate to ask questions or ask for clarification

If your child's health care team doesn't explain things clearly enough for you, speak up. It's okay to ask for clarification, especially if a doctor or nurse talks in terms that are hard for you to understand. The health care team wants to communicate well with you, but they may not realize when they're not being clear. Repeat what you heard and ask them if you got it right.

Write it down

Keep a notebook or electronic reminder handy for when you think of things to ask the doctor at your next appointment.



It may feel awkward to ask for extra time or for a clearer explanation, but it's better to ask. If a doctor can't spend more time with you right then, ask if another staff member, such as a nurse or physician assistant, can talk with you. It's important that you get all the information you need.

Write it down

Use a notebook to write down any health-related questions that come up between doctor's appointments. This helps you to remember all the things you want to talk about in the brief time that you'll be with the doctor. List your questions in order of importance to make sure that your main questions are answered.

And when you're with a doctor or other staff, be sure to take notes. Write down any specific instructions on how to care for your child. You can share these with your partner if you're the only one at the appointment.

“Always ask questions. If you don't understand the answer, ask it in a different way until you understand it. You are the advocate for your child. No one knows your child better than you, so never be afraid to speak up.”

— Dan, Grace's dad

Encourage your child to talk to you and the health care team

Children, even young ones, can give their health care team good information on how they're doing physically and emotionally.

Children don't always know how to talk about how they're feeling and may be afraid to ask questions. To help your child, consider the following tips:

- Have your child keep a list of questions to ask the doctor or nurse
- Encourage your child to talk to the doctor or nurse, and let your child speak for him or herself
- Answer your child's questions honestly and supportively as they come up
- Ask questions to see if your child understands what you're saying
- Use the child-life, art, or music therapists to help your child communicate in different ways

Remember, your strategies may vary depending on your child's age. If you're not sure how to help your child communicate, your social worker or child-life specialist are good resources.



Owen, transplant recipient

Chapter Recap:

- *Use “I” statements and start with a positive*
- *Find ways to keep both parents informed when one parent can't always be present*
- *Stay connected with your other children and show them that they're important and loved, too*
- *Organize your thoughts on paper before meeting with your child's health care team*
- *Help your child learn to talk directly to the health care team*

Visit [BeTheMatch.org/companion](https://www.BeTheMatch.org/companion) for a list of resources and tips on communication