The Parent’s Companion to Social Support:

Staying connected and getting the help you need
Allison, caregiver, with her friend
Caring for a child through the transplant process can be stressful and overwhelming at times. Staying connected with family and friends and finding support programs and resources that you find useful can help you cope with the lengthy process.

No matter your family situation, all parents and families need support when going through a health crisis with their child. It’s okay to accept help. And, it’s healthy for you to stay connected with your partner and people within your circle of family and friends. Your social worker, doctors, and nurses can also give you guidance, help you with problem-solving, and connect you with resources throughout your journey.

Just think, mountain climbers wouldn’t begin a climb without special gear, ropes, and a support team. They know it’s dangerous to go it alone. You, too, need to enlist the help of your own support team to help you through.
The purpose of *The Parent’s Companion to Social Support* is to help you learn to stay connected to your social circle and accept help when you need it most. In this chapter:

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**No one can do all of it alone**

- Staying in touch with your social network
- Connecting with your partner
- Helping your child stay connected to friends

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**Help others help you**

- How social support helps everyone
- Accepting help with grace
- Getting the help you need most
- Preparing for the unexpected
- Getting extra support

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“We asked all friends and family to draw us pictures, posters, and notes that we could use to decorate Ava’s room at the hospital. The response we got was amazing. I think it made people feel like they were doing ‘something’ to help, and it made our stay at the hospital so homey.”

— Janet, Ava’s mom
How are you doing right now?

Before you read on, take a minute to answer a few questions about how you are doing in these areas:

- Do you feel like you’re staying connected to your partner? □ Yes □ No
- Do you meet regularly with friends? □ Yes □ No
- Do you feel you are able to handle all that you need to? □ Yes □ No
- Are you ready with a list when people volunteer their help? □ Yes □ No
- Do you have enough time to handle your essential tasks? □ Yes □ No
- Do you have a support team in place to help out when you need it? □ Yes □ No
- Have you given a task to someone else today? □ Yes □ No
- Did you say “yes” to an offer of help? □ Yes □ No

If you’ve checked “No” more times than “Yes,” you are not alone. But that also means it’s time to start reaching out to others for support and help. When you are stressed, it sometimes feels easier to do it yourself rather than accept help. By sharing tasks and spending time with the people who are important to you, you’ll be able to stay healthier — both mentally and physically — and focus on what’s most important.
A shoulder to lean on

Even though your focus is on your child right now, it’s still critical that you maintain relationships with your family and friends. Staying in touch with your social network can help you feel less lonely and isolated. Here are 5 simple ways to do that.

1. **Walk it out:** Arrange a time with a friend to walk the neighborhood

2. **Talk it out:** Invite a friend over after dinner for a chat

3. **Schedule a phone date:** Arrange a definite time to connect. You’ll get through the day better when you know that you will connect with a friend later

4. **Share the things that are bothering you:** Telling your troubles to someone can ease your burdens

5. **Declare a medical-free zone:** Agree not to talk about medical things. Give yourself a mental break!

Remember, it’s okay to be brief. Even if you only have about 15 minutes to talk, still reach out. These activities can help you to relax, de-stress, and recharge.

Helping your child stay connected

Think about ways you can help your child stay connected to friends and loved ones throughout the transplant journey. Social relationships are important for the healthy development of all children. While these connections may be different while your child is recovering from transplant, they don’t have to stop.

Talk with your child’s school, coach, friends or faith community and ask them for creative ways they can help your child stay involved, even while your child is in the hospital or recovering near the transplant clinic or at home.

“Louis’s school friends reached out and offered love and support. It gave him the knowledge that he was not forgotten.”
— Mary Ellen, Louis’s mom

“We put two of TJ’s friends on the caregiver list because they were 18. He could share his feelings or just hang out with them like he would do if he were at home.”
— Sherri, TJ’s mom
Staying connected to your partner

If you have a partner, caring for a child going through transplant can be a strain on a relationship. With all you are trying to do, it can be easy to lose touch with your partner when you need that support and connection the most. Here, other parents share some of the ways they stayed connected with their partner during the transplant journey.

“We learned early on that we had to work on staying connected as husband and wife. We had to be disciplined to carve out time to talk. We found that just a few hours together outside the confines of the hospital were extremely helpful.”
— Lisa and Scott, Kameron’s parents

“It took a long time to realize that my husband and I were neglecting each other. By the time we realized it, it was like we didn’t have a marriage. We were simply partners taking care of a child. So, we started using the volunteers so we could take a walk together or go out to dinner.”
— Chinyere, Eseosa’s mom
No one can do it all alone

How social support helps everyone

Allowing others to help you benefits everyone. You benefit, of course, because it helps to get everything done and keeps you mentally and physically healthy. It helps the rest of your family, too. Your other children will likely feel better because they know someone will be there to help with day-to-day activities, like take them to school, give them a ride to practice, or cook a meal.

Parenting when you have a child going through transplant involves learning new skills, adjusting to new roles, and juggling multiple responsibilities. No one can do it all alone and it can be hard to accept help.

“People really do want to help. There is no shame for speaking up and asking for help when you really do need it.” – Sarah, Alex’s mom
But wouldn’t you want to help someone else who was in a similar situation? Of course you would. It helps to keep that in mind when you feel reluctant to accept help.

It is not a sign of weakness to accept or ask for help. It shows strength and maturity. It shows how much you care about your family because it recognizes that getting help from others will benefit your family and make you better able to help your child.

**Accepting help with grace**

You may feel uncomfortable getting help, especially if you are used to doing things for yourself or for others. One of the gifts we can give ourselves and others is to learn how to accept gifts with grace.

Remember, most people will feel glad or useful when they help you. You may not be able to return the favor to that particular person, but simply saying “thank you” is often enough.

**Find your strengths and limits**

Many parents say that, looking back, they realize they took on too much themselves. They wish they had accepted help sooner. Here’s what you can do so you won’t have any regrets later:

- Take an honest look at what you can/want to do
- Identify the things you are good at
- Be realistic about how much time you have
- Identify the strengths of your friends and family
- Determine which tasks you can give to or share with others

“I was trying to decline an offer for a gas card and the woman said to me, ‘This is the only way I am able to help you and your family. If you don’t allow me to do this, you’re robbing me of my joy.’ From that point on, we humbled ourselves and accepted what people could do and wanted to do for us.”

— Lisa, Kameron’s mom

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**Identify the strengths of your family and friends**

As difficult as it may be, let go of the things that aren’t essential for you to do. That way, you can use your energy for the things that are most important.
Getting the **help** you need most

Being ready to accept help and being specific about your needs is the key to getting the help you need most at the time you need it. Here are a few tips to help.

1. Write down things you need help with as they come up. When people ask what they can do to help, your needs are right at your fingertips.

2. Keep a list of the people who have offered to help. Call on them when a need comes up.

3. Be specific about your needs.

Most of all, don’t be afraid to accept or ask for help. Everyone needs support when they are going through a difficult time. Remember, you would likely want to help others if the tables were turned.

### Being specific about your needs

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<thead>
<tr>
<th><strong>Don’t say</strong></th>
<th><strong>Do say</strong></th>
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<tbody>
<tr>
<td>“Do you mind picking up a few groceries for me sometime?”</td>
<td>“Could you go the grocery store for me before this Friday? I can email you my list right now.”</td>
</tr>
<tr>
<td>“Maybe you could watch the kids sometime.”</td>
<td>“Next week we have several doctors’ appointments. Could you watch the kids next Friday afternoon from 2-4?”</td>
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Although it’s best to be specific, it’s also important to be flexible. So whenever possible, give people several choices on ways they can help.
Help!
The help I’m getting isn’t helpful

Although people are well-meaning, support from others can sometimes fall short in meeting your needs or expectations.

If this happens, it’s okay to say, “I really appreciate you trying to help, but right now, this isn’t helping me. It would help me more if you would please, ...”

If people offer help that you don’t need or want, thank them for their concern. Let them know you’ll contact them if you need anything. You can tell them that it always helps to receive cards and letters.

Need help organizing help?

For organizing help from others, visit: lotsahelpinghands.com

Lotsa Helping Hands makes it easy for family, friends, and community members to know what you need and when you need it when they’re rallying to support you.

“Don’t be afraid to say ‘no, we don’t need that right now.’ I had family and friends offer to clean our house, do laundry, and lots of things. I let people know that we didn’t need whatever it was now, but we might later. Responding to them that way helped them understand the journey was an evolving one, and our needs may change depending on the day or month.”

— Sherri, TJ’s mom
Prepare for the unexpected

Here are 3 important ways you can prepare for unexpected events.

Unplanned events happen. Routine doctor’s appointments can turn into a whole day of tests and visits with specialists. Trips to the hospital may happen at unexpected times. But you can be prepared.

1. Develop a list of people ahead of time who you can call on at a moment’s notice — including the middle of the night. Put their phone numbers in your cell phone or address book. These are the people who can babysit your other children, for example, if you need to spend the night at the hospital.

2. Give trusted friends and family copies of keys to your home so they can let out the dog or check in on your older children. Make a note of your important contacts and leave it by the phone for them.

3. Put together a phone tree or email list and put someone in charge of it so that if you need something unexpectedly, you only have to call one person, and that person can do the rest.

Saying thank you

Thank yous don’t have to be fancy or expensive. They can be as simple as telling people how much their help and support means, sending an email or card with just a single line of thanks, or giving a flower or plant from your garden. You can also use social media, CaringBridge, or CarePages® to express gratitude to everyone who has pitched in to help.

People will be more likely to continue to help you if they receive thanks. Without that acknowledgement, they may wonder if what they did was helpful, or they may think you don’t want or need their help any longer. Telling friends how much you enjoyed the meals they cooked for you, for example, can be all the thanks they need!
Getting extra support

Reaching out to people who are going through similar experiences can be very therapeutic.

Here are several ways you can connect with others:

1. **Request a connection** with another parent through the Be The Match Peer Connect Program (1-888-999-6743, or BeTheMatch.org/patient-peerconnect). You’ll be able to connect by phone or email with a parent who has been through the transplant journey with a child.

2. **Check with your social worker** for ongoing programs that link families or parents together.

3. **Use the hospital staff** as a source of support. Doctors, physician assistants, nurses, and social workers can be resources for information and support.

4. **Check with disease-specific and pediatric advocacy organizations** to see if they offer ways to connect with other parents. Information on some of these organizations can be found at BeTheMatch.org/companion.

5. **Use online resources** such as caringbridge.org or carepages.com to stay connected to friends and family. These are free, secure, personalized websites to help keep loved ones current and connected during difficult times.

6. **Your faith community** can be a resource for practical and spiritual support. Keep your faith leader informed of your child’s transplant journey and family needs.

“Finding others who are going through it is so important to help you feel like you are not alone. It is a special bond you make with these families who really know what it is like.”

— Heather, Owen’s mom

Chapter Recap:

- **Find ways to stay connected to your partner, friends, and family**
- **Ask others to find creative ways to bring your child’s world to them**
- **Have a plan in place when people offer help**
- **Consider online resources like Lotsa Helping Hands and enlist a friend to coordinate help, so you don’t have to**

Visit BeTheMatch.org/companion for a list of resources and tips to help you stay connected.