

The Caregiver's Companion
to Social Support:

Getting the **help you need**



“I couldn’t have gotten through this without my friends, my family and the Lotsa Helping Hands website. Everyone helped when they could. Every little bit made a huge difference.” — **Allison, caregiver**

Staying Connected

Being a caregiver can be stressful and seem overwhelming at times, but staying connected with family and friends can help you climb what you may think is an impossibly tall mountain. Many caregivers say that, looking back, they realize they took on too much themselves. They wish they had asked for help sooner.

Just think, mountain climbers wouldn't begin a climb without special gear, ropes, and a support team. They know it is dangerous to go it alone. You too need to enlist the help of your own social support team to help you through.



Jody, caregiver with her friend

The purpose of *The Caregiver's Companion to Social Support* is to help you learn to accept help when you need it most. In this chapter:

No one can do all of it alone

- How social support helps everyone
- Accepting help with grace
- Finding your strengths and limits

Help others help you

Have a plan: Be ready when friends say “yes”

- Preparing for the unexpected
- Saying thank you
- Staying connected
- Getting extra support

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 you are able to handle all that you need to?..... Yes No

Are you ready with a list when friends volunteer their help?..... Yes No

Do you have enough time to handle your essential tasks?..... Yes No

Do you meet regularly with friends?..... Yes No

Have you been able to delegate a task today?..... Yes No

Did you say “yes” to an offer of help today?..... 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 help. When you are stressed, it sometimes feels easier to do it yourself rather than ask for help. By sharing tasks, you will be able to stay healthier—both mentally and physically—and focus on what’s most important.



Allison (center), caregiver with her daughter and sister-in-law

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 your loved one, because they may worry about you, and feel relieved that you are getting the help you need.

Caregiving involves learning new skills, adjusting to new roles, and juggling multiple responsibilities. No one can do it all alone but it can be hard to ask for help. Many people worry about shifting a burden to other people who are busy with their own lives.



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 ask someone for help.

It is not a sign of weakness to ask for help. It shows strength and maturity. It shows how much you care about your loved one because it recognizes that getting help from others will benefit your loved one and make you better able to provide the care you want to provide.

Accepting help with grace

You may feel uncomfortable receiving 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 in kind to that particular person, but you may be able to find ways to give back to the larger community in other ways, or to others in need.

Find your strengths and limits

Many caregivers say that, looking back, they realize they took on too much themselves. They wish they had asked for 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

Identify the strengths of your family and friends

As difficult as it may be, you must try to 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 to you.



5

Steps to getting the **HELP** you need most

- 1** Make a list of the specific things that need to get done at this moment.
- 2** Circle those tasks that you need/want to do by yourself. Try not to pick more than five.
- 3** Make a second list of all the people you can think of in your family, your friends, people at work, in your neighborhood. Think about their strengths and current life situations.
- 4** Match the needs on your list with those people in your support network who have the time and the ability to meet those needs. For example, if you need help with meals, identify someone who loves to cook who would be willing to prepare and freeze some main dishes for you.
- 5** Call (or ask someone else to call) or email and ask those on your list to help you out with the specific tasks you have selected.

Look at this often and revise it if you need to, especially if it appears that you are asking just a few people to do the majority of tasks. And if you feel that the help you're receiving still isn't enough, consider reaching out to others. Maybe it's someone from a local community group or even a co-worker. You may be surprised to learn how many people will want to help.

“Looking back, I wish I would’ve let others help more. I didn’t realize how much I was holding back from them until I finally let them in. They wanted to help us so deeply but didn’t know how.” – **Kate, caregiver**

A photograph of three young women standing outdoors, laughing and talking. The woman in the center is wearing a pink t-shirt and patterned shorts. The woman on the left is wearing a blue t-shirt and white shorts. The woman on the right is wearing a light blue t-shirt and dark pants. They are all smiling and looking at each other. The background shows green trees and a bright, sunny day.

Have a plan: **Be ready**
when friends say “yes”

Kate (center), caregiver with her friends

Help others **help you**

Be ready and be specific when you ask your friends to do tasks for you. Here are some tips:

don't say

“Do you mind picking up a few groceries for me sometime?”

“Maybe you could watch the kids sometime.”

do say

“Could you go the grocery store for me before this Friday? I can email you my list right now.”

“Next week we have several doctors’ appointments. Could you watch the kids next Friday afternoon from 2-4?”

Although it’s best to be specific, it’s also important to be flexible. So whenever possible, give your friends several choices on ways they can help. Remember—they may not do things the same way as you would. Let it be okay and don’t forget to express gratitude for the help you receive.

Need help **organizing help?**

For organizing help from others, visit: **lotsahelpinghands.com**

Lotsa Helping Hands allows friends, family, colleagues and neighbors the opportunity to offer help to loved ones at crucial times.

“The Lotsa Helping Hands website was the biggest way I asked for help. It was a wonderful system so that once it was established I didn’t have to technically ask anyone. I also assigned some friends to be coordinators and have used them to ask the group of members for things if I’ve felt too strange doing that.” —**Allison, caregiver**



Allison, caregiver

“When people brought us food, they left it in a cooler on our porch and slid a note under our door so we knew it was here.”

—Allison, caregiver

“I set my ego and pride on the curb and asked everyone for help. I posted tasks on the website that people could sign up to do. I was like a marathon runner — anyone who held out a cup of water I took.” —Clark, caregiver



Jody (left), caregiver with her friend

“I was so amazed at the network of friends willing to make dinner or give a ride to the doctor.” — **Jody, caregiver**

Prepare for the unexpected

Here are  important ways you can prepare for unexpected events.

-  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 and day planner. These are the people who can babysit, for example, if you need to spend the night at the hospital.
-  Give trusted friends and family copies of keys to your home so they can let out the dog or care for your children. Make a note of your important contacts and leave it by the phone for them.
-  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 you can let him or her do the rest.

So you've scheduled your week, and you've found enough people in your social network to help you handle all the tasks ahead. Go ahead and pat yourself on the back!

But you must still be prepared for unpredictable events, such as when a routine doctor's appointment turns into a whole day of tests and visits with specialists.

Saying thank you

Thank yous don't have to be fancy or expensive. They can be as simple as telling

someone 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.

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!

Stay connected

With all that you are trying to do, it can be easy to lose touch with family and friends when you need that support and connection the most. It's critical that you maintain your relationships with those who are important to you so that you don't feel lonely and isolated. Here are six 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 You can be brief:** Even if you only have about 15 minutes to talk, still reach out
- 4 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
- 5 Share the things that are bothering you:** Telling your troubles to someone can ease your burdens
- 6 Declare a medical-free zone:** Agree not to talk about medical things or caregiving. Give yourself a mental break!

As a bonus, these activities will help you to relax, de-stress, and recharge so that you can be a better caregiver.



Allison (right), caregiver with friend

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.

Getting extra support

Reaching out to groups of people in your community who are going through similar experiences can be very therapeutic.

Here are several ways you can connect with community-based organizations:

- 1 Check with your local cancer center** for ongoing programs that link families together. Do they have any support groups or a peer-to-peer program for people with cancer, survivors, or caregivers? If there are no formal programs, contact your social worker and find out if they know of other families and caregivers that could talk with you.
- 2 Use the hospital staff as a source of support.** Physicians, physician assistants, nurses, and social workers can be invaluable resources of information and support.
- 3 Check in your community** for informational or support services for cancer families or caregivers. Often these are listed in the local newspaper. Two organizations that coordinate local support groups are the American Cancer Society (1-800-ACS-2345, or www.cancer.org) and the Leukemia and Lymphoma Society (1-800-955-4572, or www.leukemia-lymphoma.org)
- 4 Use online resources** such as caringbridge.org or carepages.org to stay connected to friends and family. These are free, secure, personalized websites to help keep loved ones current and connected during difficult times.

“I used a website (Caring Bridge) to keep everyone informed. This cut down on the phone calls and emails. I didn’t answer my phone unless it was an immediate family member.”
—Clark, caregiver

Chapter Recap:

- *Have a plan in place when people offer help*
- *Consider online resources like Lotsa Helping Hands to coordinate help, so you don’t have to*
- *Stay connected to those closest to you; try scheduling a weekly phone date to stay in touch*

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

