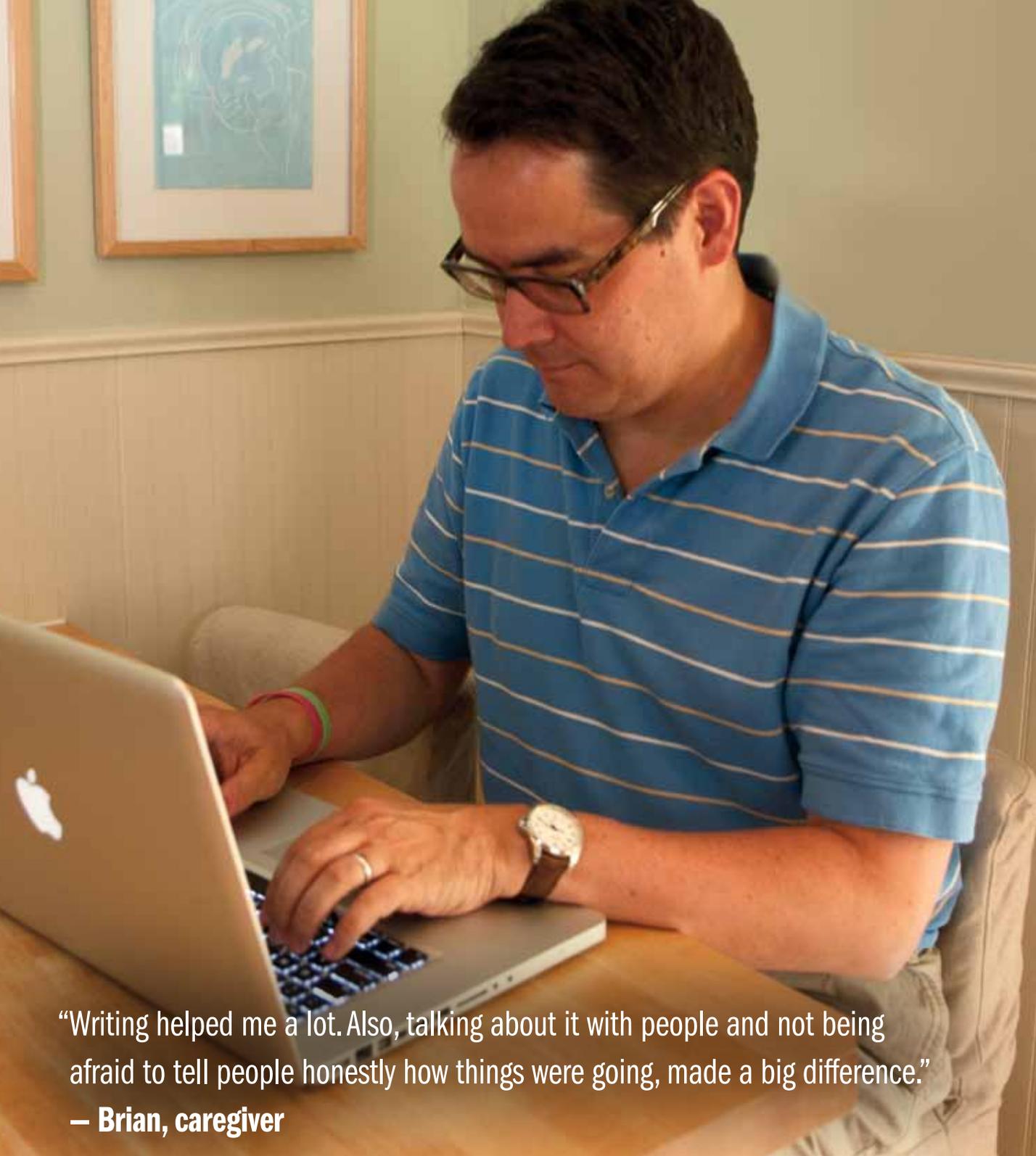


The Caregiver's Companion
to Communication:

Developing skills for
**effective
communication**



“Writing helped me a lot. Also, talking about it with people and not being afraid to tell people honestly how things were going, made a big difference.”

— **Brian, caregiver**

What to **say**— Finding the words

Communication is important in your many roles as caregiver: as patient advocate in communicating with the health care team, as partner and caregiver in understanding and supporting your loved one, and in communicating with family and friends to request help or give updates.

Therefore, being able to communicate simply and directly – while avoiding misunderstandings – is critical for everyone involved. This chapter will provide some useful tips on how to communicate clearly.



Mitch, caregiver

The purpose of *The Caregiver's Companion to Communication* is to help you develop and use more effective ways to communicate with your loved one, your loved one's health care team, and others. 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
-

Be situation savvy

- Help your health care team help you
 - What to ask when a new medicine is prescribed
 - Learn skills to help you in an emergency
-

Family matters

- Connecting with your loved one
- Communicating with family and friends

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 take notes during doctors appointments?..... Yes No

Do you always know the right words to say to comfort your loved one? Yes No

Are you prepared to communicate effectively in an emergency? Yes No

Do you have a caregiver's notebook to keep you organized? Yes No

Do you feel comfortable talking with your friends and family?..... 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



Allison, caregiver with her sister-in-law

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...

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 or want before you communicate with others. When we are not clear with others about what we really need or want, we get frustrated when others don't respond the way we want them to.

When people talk, they generally want one of four things from the person they are communicating with:

- Information
- Advice
- Understanding
- Reassurance

If you know what you are looking for, you can phrase your request to maximize getting what you need.

For example, let's say your loved one has been experiencing dizziness at home 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 husband has been having dizzy spells at home. He has not experienced this before. I'd like to know what could be causing these and if there is anything we can do to stop them."

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 aggressive to the point that others don't want to deal with you.

Here are some ways to phrase 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 husband's pain?”

say

“I am concerned that my husband is in so much pain. Is there anything you can do for him?”

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

Screaming or pounding your fist on the table

say

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

I had to be a strong advocate for my husband's health and care. When doctor's said I could contact them, I would take them up on it, even emailing in the middle of the night if I had a concern.” — **Allison, caregiver**

Be situation savvy

Find the tools in this section to communicate in specific situations such as with health care professionals, pharmacists, and family and friends.

Help your health care team help you

Coordinating care for your loved one isn't easy, especially when dealing with multiple health professionals, in different medical specialties, and likely at several different locations. Unfortunately, this increases the chance of miscommunication, which will cause you additional stress.

There are lots of simple things you can do to improve communication.

Don't hesitate to ask questions or ask for clarification

If the professionals on your loved one's health care team do not explain things clearly enough for you, speak up. It's okay to ask for clarification, especially if a medical provider speaks in terms that are hard for you to understand. Most providers want to communicate well with patients and families,

but they often do not realize when they are not being clear.

It may feel awkward to ask for extra time or for a clearer explanation of information, but it is better to ask. If a doctor cannot spend more time with you right then, ask if another staff member, such as a nurse or physician assistant, can talk with you. After all, the burden of care is on your shoulders when you are at home caring for your loved one. You are entitled to get all the information you need.

Write down everything

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 discuss in the brief time you'll be with the doctor. List your questions in order of importance to ensure that your main questions are addressed.

And when you are with a doctor or other health care professional, be sure to write down any information you receive, especially any specific instructions on home care for your loved one.

“I put together a 3-ring binder and used it to keep track of everything. If someone else brought Sean to a doctor appointment, I had them take notes so I could stay up to date.”

— Allison, caregiver

Write down everything

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



Skills to help you in an emergency

Caregivers say that one of the hardest parts of being a caregiver is monitoring their loved one's symptoms and deciding when it is an emergency and when to call the doctor.

To prepare, ask the doctor or health team what they would consider an emergency and how you should reach them. Write down the emergency phone numbers in the notebook so that you have them handy. Make sure you have numbers for both daytime hours as well as after hours.

If you think your loved one's condition may be an emergency, call 911 even if you are not absolutely sure.

Be sure the person you talk to understands that you feel this is an emergency. You might say, "I am very concerned about my loved one. I think it may be an emergency. Can you help me?"

Try to have the answers to as many of the following questions before you call:

- When did the problem start?
- What do you think brought it on?
- What makes it feel better?
- What makes it worse?
- What is the person's temperature?

Be sure you also have a list of current medications and doses, and the most recent time each one was taken.

What to ask when a new medicine is prescribed

If your loved one starts a new medication, here is a list of questions to ask the doctor or pharmacist. Write down the answers, put a date on it, and keep it with your medication list.

- What is the medicine for?
- Will the medicine interact with other drugs taken?
- How often should the medicine be taken?
- What is the dose (how much should be taken each time)?
- How long should the medicine be taken?
- Should the medicine be taken with food or on an empty stomach?
- Are there special instructions, like avoiding alcohol, sunlight, or certain foods?
- What are the possible side effects?
- Can we prevent any side effects?
- Which side effects are serious enough to require urgent medical care?
- What should we do if a dose is missed?



Family matters

Sometimes, it can be hard to find the “right” words to help a loved one. There may not be anything that we can say to make them feel better. But you can still show love, support, and caring with a gentle touch, a holding hand, or just sitting with the person for a while.

If you aren't sure what to say, you can always say, “I'm not sure what to say. Can I just sit with you for a while?”



Allison, caregiver, with her husband Sean

Connecting with your loved one

If you are a caregiver for a partner in a marriage or committed relationship, your role in the relationship has shifted from roles as equal partners to unequal roles of patient and nurse. It can be hard for you as the caregiver to know when to encourage and nudge the patient to do certain things and when to just support or protect them. You also can get so used to taking care of your loved one that it can be hard to let go of those roles later. The most important thing you can do is try to keep the lines of communication open and let each other know what you are feeling.

Here are some tips to help you support your loved one:

don't

- Force your loved one to talk if he/she is not ready
- Tell your loved one how he/she “should” feel
- Assume that it is your fault if your loved one is feeling down or depressed
- Feel that you must cheer your loved one up in order to be helpful
- Try to talk your loved one out of how he/she is feeling

do

- Let your loved one express his/her feelings
- Encourage him/her to identify causes for the feelings
- Actively listen and try to understand the feelings
- Offer support and encouragement
- Let him/her know that the feelings are normal
- Encourage your loved one to talk to friends, other survivors, or a professional counselor



Sharen, caregiver, with her husband Mike

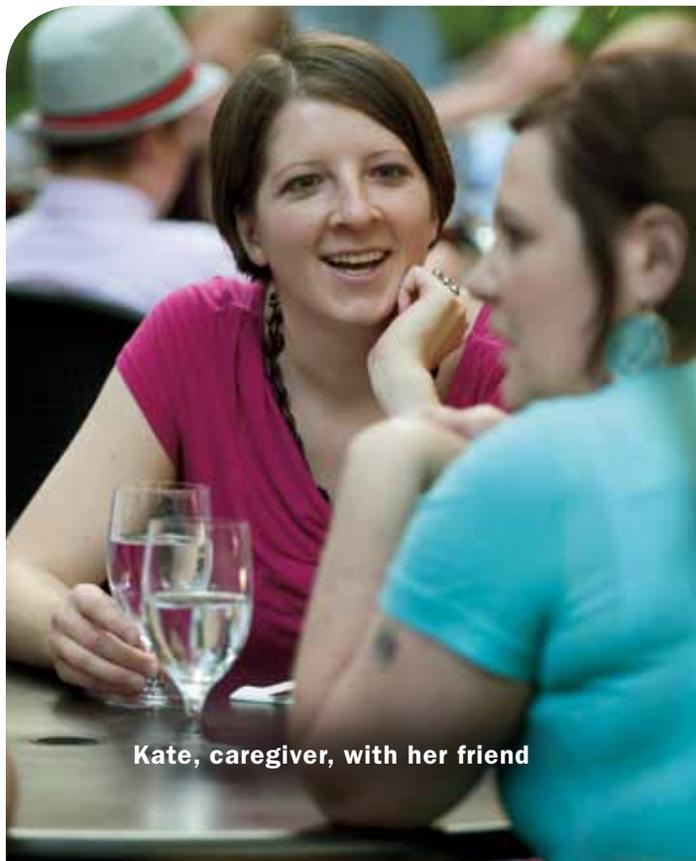
Talking with family and friends

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 other 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 that 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 counselor to help facilitate a difficult conversations

You may find that friends and distant family may often call or email you to ask how your loved one 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. You can use Facebook 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 friends and family.



Kate, caregiver, with her friend



Brian, caregiver, with his daughter

Chapter Recap:

- *Organize your thoughts on paper before meeting with your health care team*
- *Use “I” statements and start with a positive*
- *Support your loved one by letting him/her express feelings; but don’t force conversation if your loved one is not ready*

Visit **BeTheMatch.org/companion** for a list of resources and tips on communication

