

Skill-Building Tip Sheet #SB5



Communicating with Health Professionals

Many caregivers need information about how to provide care.

Why do you need information? *(Put an X beside all that apply to you and add more if needed).*

- ☐ No prior knowledge about stroke
- ☐ Never been a caregiver before
- ☐ The stroke was sudden, so there was no time to learn
- ☐ Do not have enough information
- ☐ Do not know what to expect
- ☐ Taking care of the survivor is complex
- ☐ Taking care of the survivor changes many things in life
- ☐ Have to do new things that the survivor used to do
- ☐ Other _____

Many caregivers have trouble asking for information. **Why do you have trouble asking for information?** *(Put an X beside all that apply to you, and add more if needed).*

- ☐ Do not feel comfortable talking with the doctor or others
- ☐ Doctor or professional doesn't seem to want to talk to you
(they are only focused on the survivor)
- ☐ The survivor refuses to seek care
- ☐ Afraid to question doctors or professionals
- ☐ Think doctors or professionals are too busy
- ☐ Told different things by different people
- ☐ Can't get past someone to ask the doctor or professional
a question directly
- ☐ Don't know what to ask
- ☐ Forget questions before the visit
- ☐ Don't understand medical terms used by doctors or
professionals
- ☐ Can't read very well, or can't hear
- ☐ Too emotional to focus on what is being said

- ___ Can't process information very well, or have trouble remembering
- ___ Don't trust the doctors or professionals
- ___ Other _____

How can I as a caregiver ask for information from professionals?
Whatever the reasons, here are some tips that you might find helpful:

- **Use the worksheet at the end of this tip sheet.** Fill in why you need information, why you have trouble asking for information, and strategies you can use. There are also spaces where you can prepare by writing your questions ahead of time.
- **Because health professionals are busy, prepare your questions ahead of time.** This will keep you from forgetting important questions when you are talking with the doctor or other professionals. It will also save time during the clinic visit or while the doctor or professional is on the telephone with you.

Here are some examples of how you can word your questions:

Problem asking questions.	How to word your question.
Doctor or professional doesn't seem to want to talk to you. (They are only focused on the survivor).	"As this person's caregiver, I need to know...." "How can I help them with ____?" "Since I am home with them every day, I need to know ____."
The survivor does not want to seek care when they need it.	"As this person's caregiver, I need to know what to do about ____." "My [relative] does not think this is a problem, but I am worried about ____."
Think the doctor or professional is too busy.	"I know that you are busy, but I really need to know ____." "It is urgent that I know ____."
Told different things by different people.	"That is not what _____ said about _____."

	“_____ told us to _____, but now you are telling us to _____. Which should we do?”
Can't get past someone to ask the doctor or professional directly.	“I need to talk to _____ directly about an urgent concern.” “I have an emergency (or urgent need) and need to talk to a doctor.” “I am very concerned about _____ and I think that it is very urgent.” “I have a question about _____ and I'm not really sure if it is an emergency. Who can help me?” “I need to talk directly with _____. Can they come to the phone? If not, when can I expect their call?”
Don't know what to ask.	“I'm not sure I understand all of this. What is the most important thing I need to do (or know)?” “What do most people need to know about _____?”
Don't understand medical terms used by doctors or professionals.	“What does _____ mean?” “What are you saying in simpler terms?” “I don't understand what you are saying.” “You sound like you are talking a foreign language. What are you trying to tell me?” “I don't know those big words you are using.” “What is the bottom line?”

Can't read very well or can't hear very well.	"I don't have my glasses. Would you explain this to me?" "Reading is not my best talent. Would you tell me what this is about?" "I am hard of hearing. Please speak up."
Too emotional to focus on what is being said.	"I am not dealing with this very well, but I don't want to miss what you are saying." "Can you write this down for me so I can think about it when I am not as upset?"
Not able to process information very well or trouble with memory	"Do you mind if I tape record what you are saying? I don't want to miss what you are telling me." "Can you write down what you are telling me, so I don't forget?"
Don't trust the doctors or professionals.	"Where can I get a second opinion?" "What other options are there?" "Where can I find more information about this?"

Here are some other tips to think about:

- Put a pad of paper and a pen next to your telephone at home or use a notebook to stay organized.** When you have a question, write it down. Use the list to help you organize your thoughts when asking questions over the telephone. Practice or role play the questions with someone else before calling the health professional. Take the list of questions with you to doctor visits. Write down the answers while you are talking to the doctor or professional. Having your list in front of you and taking notes will help you organize your thoughts and make you feel more confident in asking questions. Some caregivers take a notebook with them that also has a list of the

survivor's medications, treatments, diet, and other important information about their care. Keeping your list on a mobile phone, iPad, tablet, or computer may be helpful for those who like to use technology.

- **Caregivers have a right to ask doctors and other professionals questions.** Think of you and the survivor as customers. You are paying doctors and professionals for their time and expertise. They should never be too busy to answer your questions. They don't know what your questions are unless you ask them. ***Be respectful, assertive, and firm, but avoid showing your anger or being demanding.*** Here are some general questions you can ask:
 - What are warning signs of another stroke?
 - What are common complications I need to watch for?
 - When should I call 911?
 - When should I notify you? What number do I call?
 - What symptoms, impairments, or behaviors might I expect to see as the survivor recovers?
 - How long does it take to recover with rehabilitation?
 - What lifestyle changes can we make to prevent another stroke?
 - What can I do as a caregiver that will help the most?
 - Where can I find more help or information?
- **If you feel angry or upset** as a caregiver, describe the skill or problem you are having, then say how it makes you feel.

"I am having trouble with _____. This really makes me feel _____." OR... "I feel _____ when I try to (insert skill) _____." THEN ask, "How do I _____?"

Try to separate your emotions from the skill or problem when you talk with the doctor or health care provider. This will help you describe the trouble you are having. It will also help you define your emotions and to seek support from them.

Write what you would say to the doctor or health care provider about a skill or problem that you are having:

Doctors and other professionals are human. It is their job to provide care and to answer questions. Just because they are experts doesn't mean that you are not allowed to ask them questions. ***Even though care is focused on the survivor, you have a right to ask questions as their caregiver.*** Speak up when you don't understand something.

- **There is no such thing as a dumb question.** Don't be afraid to ask simple questions. Realize that many other people probably have asked the same question.
- **Tell the doctor or professional when you do not understand what they are saying.** Sometimes they forget that survivors and caregivers have not had a medical terminology course. Ask them to tell you in everyday language.
- **Practice asking questions to a friend who is pretending to be the doctor or professional.** This can help reduce your fear.
- **In addition to the survivor, bring a trusted family member or friend to the appointment with you.** They can take notes, or help you ask your questions. They can also be there to offer moral support.
- **Speak up when you are told something different.** The doctor or professional should know if someone else is telling you something different. Let the doctor or professional help you decide whose advice you should take.
- You may find that someone is keeping you from talking to the doctor or professional directly. **You have a right to insist that you talk directly to the doctor or professional.** Be direct. Tell them to have the doctor or professional call you back if they are not available. Find out when you can expect their call.
- **Tell the doctor or professional if you cannot read very well or if you cannot hear.** They will understand. Many written materials are not clearly worded. There are ways to deliver information if you cannot hear. The doctor or professional should find another way to give you the information.

- **Learn how to manage your emotions.** Stress can shut down your ability to process information. It is difficult to focus on new information when your brain is troubled by negative thoughts and emotions. Talk to a friend or family member about how you are feeling. Talk to your doctor too. There are medications and counseling that can help you feel better. Try to control your anger or frustration when asking questions.
- **Don't be afraid to tell the doctor or health professional if they are talking too fast.** Take notes or ask them if you can tape record the conversation. You can then listen or look at your notes again to see if you can understand things better. This also helps you remember what was said. Taking a friend or family member for an extra set of ears helps too.
- **Get plenty of rest when you can.** When you are tired, it is difficult to remember and process information.

When do I need to contact a professional?

Anytime that you have a question. To find out what questions to ask which health professionals, check out **Tip Sheet #7 Who to Call for Advice.**

A worksheet for asking for information

Why do I have trouble asking for information?		
Why do I need information?	Why do I have trouble asking for information?	
What strategies can I use to get information? If I feel angry or upset, describe the skill or problem, then say how it makes me feel. For example: "I am having trouble with _____. This really makes me feel _____." OR "I feel _____ when I try to (insert skill) _____." THEN "How do I _____?"		
My list of questions		
My question is...	Whom do I ask?	What did they say?
My question is...	Whom do I ask?	What did they say?
My question is...	Whom do I ask?	What did they say?
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A worksheet for asking for information (extra)

Why do I have trouble asking for information?		
Why do I need information?	Why do I have trouble asking for information?	
What strategies can I use to get information? If I feel angry or upset, describe the skill or problem, then say how it makes me feel. For example: "I am having trouble with _____. This really makes me feel _____. " OR "I feel _____ when I try to (insert skill) _____. " THEN "How do I _____?"		
My list of questions		
My question is...	Whom do I ask?	What did they say?
My question is...	Whom do I ask?	What did they say?
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