



GETTING WHAT YOU NEED (SELF ADVOCACY)



This guide will help to answer questions about how to get what you need after a stroke, whether you are a caregiver or a stroke survivor.

This applies to information, advice, direction and resources. The technical term for this is ‘self-advocacy’. Your grandmother might have called it ‘standing up for yourself’! Most of it boils down to good communication and good customer service. It all helps in getting good guidance, information and advice for stroke recovery in the community.

WHAT IS SELF ADVOCACY?

The definition of advocacy is “active support,” especially the act of pleading or arguing for something. In this case it is for the well-being of yourself or your loved one. To be a self-advocate is to be a supporter, believer, encourager, and activist of and for yourself. It is standing up for your needs in a clear, specific and firm way. It is not being afraid to ask for help when you need it.

WHY IS SELF ADVOCACY IMPORTANT?

Suffering a stroke is often an overwhelming experience that takes away a sense of control – over physical and mental health and well-being. Practicing self-advocacy allows you to empower yourself – to personally take responsibility in making the most of your recovery from stroke. You have a say in what you want and need, and can directly impact your own quality of life.

The needs and the resources available to meet these needs are key. Your social worker and therapists are good sources of accurate, reliable information on options that fit your values and resources. There are tough questions that must be asked for the sake of everyone involved. As difficult as they may be, if these questions are answered, everyone will face the new situation having made a conscious choice. Remember, whatever decisions you make should be based on your own individual situation, not on what someone else did or what you think is expected of you.

PREPARATION

There are many considerations which should go into planning for the time after the stay in hospital following a stroke is over. To get ready to speak to anyone you are seeking information from:

- » **Write down your questions, thoughts and concerns.**
- » **Keep your diary or notebook handy.**
- » **Put your questions in order of importance so the urgent ones are answered first.**
- » **Be patient. Finding the right answer or person may take time.**
- » **Find the person who can give you the answer you need.**
- » **Be sure the person has time to speak with you before you start your conversation.**

EFFECTIVE COMMUNICATION

A lot can be gained by effective communication between stroke survivors, caregivers and healthcare professionals and other service providers. It can result in:

- » **Better care for the stroke survivor.**
- » **Less stress and illness for the caregiver.**
- » **More efficient use of everyone's time.**
- » **More satisfaction for all concerned.**

To get the most out of any communication:

- » **Be very clear and concise.**
- » **Never apologize for asking for help.**
- » **Speak up ... never assume others know what you need.**

COMMUNICATING WITH HEALTH CARE PROFESSIONALS

Be sure the health care professional understands the caregiver's role in the stroke survivors life.

If your loved one is not willing or able to take instruction, make sure the professional tells you all important information. Clearly explain your situation to help the professionals make practical suggestions you can use. (Example: "It's better for my job if we can come early in the morning.")

Educate yourself about stroke. Organize your questions about the information you've read and be concise. Don't be afraid to ask questions, but try to be specific. Especially ask what to watch for that would indicate an emergency situation for your loved one.

Keep records about things like sleeping, eating and emotional episodes, symptoms, medication, habits, etc. The more detailed information you have, the easier it is for the professional to work out the best solution.

Take time to make decisions about care. If it means having to wait a few days and it's not life-threatening, tell the professional you need some time to discuss with your loved one or your family.

Appoint one family member as the main contact with healthcare professionals when possible. This will avoid confusion and save time for the professionals.

Hold conversations in appropriate places – not waiting rooms or corridors. You deserve to receive full attention in an appropriate room or office.

Ask about other resources. Professionals can often point you to support groups, suggest help in paying for medications, in-home care and other

things that you need as a caregiver. Have everything that's on your mind written down before you arrive. Once you're there, you might forget and start rambling. The more organized you are, the more help you can get. Ask for a consultation appointment if you've got a lot of questions. That way the professional will be prepared to sit down with you and talk for an extended time.

Understand the limits. The professional can't answer some questions, especially those beginning with the word "why" or those that deal with your family problems.

Separate your anger and sense of frustration about not being able to help your loved one from your feelings about the professional. Remember, you and the professional are on the same side.

Feel free to change. If you feel that the professional is just not a good fit — either professionally or emotionally — ask to see a different professional in the group or seek out another place of care.

Be appreciative. Don't forget to thank the professional for all that he or she is doing. A little kindness and recognition goes a long way.

IF YOU ARE NOT GETTING WHAT YOU NEED

- » **Make an appointment to discuss your concerns in person.**
- » **Stay calm, but insist on getting the answers you need.**
- » **It is the service provider's job to answer questions or direct you to someone who can.**
- » **If one person doesn't give you what you need, look elsewhere.**
- » **Don't feel guilty. You have the right to every available option.**
- » **Remember: you are the expert in your own situation and an important part of the team. It is important for you to understand all you can.**



Sincere thanks to the Stroke Recovery Association of British Columbia, an affiliate of After Stroke, a program of March of Dimes Canada, for creating this resource - your experience and support have added incredible value.

For more information on Guides to Recovering from a Stroke visit our website at afterstroke.marchofdimes.ca