Being a proactive patient means taking the lead in your treatment and care. It includes making treatment choices and working with doctors, prosthetists, and therapists to achieve these goals. Being proactive also means asking questions, doing research, and speaking up for what you believe in and feel important. Sometimes this is called “information gathering” or “problem-solving.” I simply call it being a “proactive patient.”

You are the very best person to advocate (speak up) for yourself. While your doctors and friends can offer advice and support, you are the only one who is at ALL phases of your treatment and care. Therefore, you need to speak up for yourself even if you are feeling afraid, depressed, frustrated, tired, or in pain.
Ways to be a proactive patient

Maybe you never thought of yourself as a proactive patient. After all, you always want to be nice -- not rude, or a “squeaky wheel.” The good news is that even nice people can be proactive.

“The squeaky wheel gets the grease” is an old saying that is true today. You are not likely to get what you want if you are very shy, withdrawn, or undemanding. I have seen that proactive patients who expect and ask for more, get more.

The more you speak up for yourself, the easier it gets. You can start by doing your “homework” and researching a topic. This way, you have the information you need and can feel confident that you know what you are talking about. You are more likely to be proactive when you see it leads to results you want.

Speak up for the young and old

While it is always good to be proactive, it is even more important when patients are very old or very young. This includes adults aged 60 and over, as well as parents of infants or young children. Patients of all ages deserve a chance to be successful.
Sometimes healthcare providers have lower recovery goals for older adults who need prosthetics. This may be due to concerns about a patient’s age or other health issues. But lower goals can be wrong. I have worked with hundreds of people in their 70s, 80s and even 90s who use prosthetics with success. Older adults can be proactive by talking with healthcare providers about the goals they want to achieve. They can also be proactive by talking with their insurance company about ways to pay for these goals.

Some doctors and prosthetists believe that babies and young children do not need prosthetic care. But this is not always true. There are many reasons that parents should consult with a prosthetist as soon possible. You can do this even if you decide not to start prosthetic care now.

**Be proactive throughout treatment and care**

You can be proactive even before surgery. This is a good time to talk with doctors and other healthcare providers about:

- Surgery. This includes the surgery choices you have and what to expect
when surgery is over

- Prosthetic care. This includes use of Immediate Post-Operative Prostheses (IPOPs)
- Ways to learn more. Ask for a list print, online, and phone resources to learn more. If you want even more information, you can also do your own research on the Internet or in medical and prosthetic journals.

Ask for a second opinion (preoperative consultation) before you agree to surgery. This means talking about treatment choices with a doctor or prosthetist new to your case. You can ask for a second opinion even if your doctor does not suggest it.

When you need emergency surgery and cannot get a second opinion, ask to talk with a prosthetist soon after surgery is over. You might also want to speak with a “peer visitor” who has been certified by the Amputee Coalition of America (ACA). A peer visitor is someone who has gone through the same kind of surgery as you. To learn more, call the ACA at (888) 267-5669.

You can also be proactive during rehabilitation. At this time, you will work closely with a prosthetist, physical therapist, and maybe an occupational therapist. These healthcare providers will teach you techniques to do and talk
with you about treatment options. If you ever feel that your prosthetist or therapist does not listen to you, ask to meet with someone new.

Being proactive during rehabilitation means speaking up about your treatment goals. It also means asking lots of questions, learning about prosthetic products, and doing your own research. For instance, you could go online to learn more about choosing and fitting a prosthesis.

Sometimes patients need a second (revision) surgery to achieve better prosthetic fit and function. If this happens to you, be proactive and:

- Get second opinions from a doctor and prosthetist
- Talk with 1 or 2 patients who have had revision surgery like yours
- Do your own research about revision surgery and prosthetic options

**Learn about prosthetic choices**

At times, you might feel overwhelmed with all the prosthetic choices for socket designs, feet, hands, knees, and other components. Talk with a prosthetist to learn more about these choices. And also think about what matters to you. This includes how active you want to be and what you like to do.

Then do your own research about the components that interest you. One good
way is by talking with other people who use them. But keep in mind that just because a component works well for someone else, it may not be as good for you.

Some prosthetic makers let patients try certain components for a period of time. Ask if this is an option. Do not, though, pay much attention to the product ads as they are written to boost sales.

Your insurance company, managed care plan, or Medicare may limit your choices of prosthetics and components. Be prepared to speak up if you do not agree with what they will pay for. You can also ask your doctor or prosthetist to help you get these items paid by insurance. If these efforts do not work, talk with your healthcare providers about next-best choices. Sometimes, you may need to pay out-of-pocket (by yourself) for a component.

**Contact the Amputee Coalition of America (ACA)**

The ACA is a great resource to help you be a proactive patient. It has information about amputation, prosthetics, rehabilitation and lifestyle recovery. The ACA has a newsletter and website with an online support group, catalog of amputation-related materials, and links to other helpful resources. The ACA website is at [www.amputee-coalition.org](http://www.amputee-coalition.org)
About the Author

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Photos courtesy of Hanger Prosthetics & Orthotics, Inc.