When you buy a new car or a washing machine, it comes with an owner’s manual to guide you through your ownership experience. The manual contains diagrams and instructions that you can use to familiarize yourself with basic operations, tips about how and when to use advanced features, maintenance schedules to keep things running at their optimal level, and often a toll-free phone number to call for support if you have trouble finding answers to your questions on your own.

After a construction accident in 2002, I became the owner of a brand-new, custom-made, prosthetic right arm and that new and very foreign-looking device did not come with an owner’s manual.

I’m not suggesting that it is even possible to create a comprehensive guide to assist those of us who live with an upper-limb difference. In a world designed for folks with two fully functional arms and hands, the challenge that those of us with an upper-limb loss or absence face is to find adaptive ways to thrive. We all have different situations and aspirations. Specific tips and solutions that allow a young woman who was born without her left arm to live to her fullest potential may not apply to a middle-aged man who lost both of his hands on the job.

Choosing whether or not to wear a prosthesis and deciding which type is appropriate can be particularly difficult. Prosthetic devices vary greatly in their composition and method of operation. Often it is only by trial and error that we find what works best for us. Trying to figure everything out on your own can be frustrating and can take a great deal of time. While it may feel like you are alone in your efforts, it is important to understand that there are resources available to help you find your way. There is no single place to get all of your answers, but tapping into the knowledge of healthcare professionals and your amputee peers can often put you on the fast track to reaching your personal goals.

Choosing the right healthcare professionals can have a big impact on your quality of life. Before accessing the services of a physiatrist (rehab doctor), prosthetist or occupational or recreational therapist, be sure to ask how much training and experience they have in working with people with your type of amputation. Check with professional organizations such as the American Board for Certification in Orthotics, Prosthetics and Pedorthics, the Board of Certification/Accreditation International, and the American Occupational Therapy Association to see if there...
are professionals in your area who specialize in upper-extremity amputee rehabilitation. There are centers of excellence across the country, and many have free evaluation clinics. Wherever you go, try to keep an open dialogue with your practitioners. Let them know your desires and goals and work with them to find your personal solutions. Keep in mind that no one individual is likely to have all of the answers, and if someone tells you that something you want can’t be done, it may be best to seek a second opinion.

Spending time with other people who are living with a similar limb loss can also set you up for success. The Amputee Coalition of America (ACA) has a National Peer Network that you can use to get in touch with other people who live with your type of amputation(s). One of the biggest misconceptions about peer support groups is that they exist only to help people who are having emotional difficulty in coping with their situation. The ACA’s certified peer visitors are trained to provide emotional support when it is needed, but they can also provide valuable tips about the things they do and the equipment they use to adapt to their upper-extremity limb loss/difference. Peer visits can be requested simply by calling the ACA at 888/267-5669. Upon receiving your request, the ACA will make every attempt to put you in contact with someone who is the best fit for your age, gender, level of amputation and location.

It is truly remarkable to see how other people adapt to their situations. I find that every chance I have to meet another arm amputee ends up being both a teaching and a learning experience. About 6 months into learning how to use my prosthetic hook, I saw a man in a diner cutting his breakfast steak. He was holding the knife in his prosthetic hook in a way I hadn’t thought of on my own. I tried holding it his way and I was amazed at how well it worked. He invited me to sit with him and we exchanged our “How did it happen?” stories – mine, 6 months earlier in a construction accident; his, 33 years ago in a field in the Vietnam War. He was the first man with a prosthetic right hand that I had met since my accident, and in 10 minutes he talked me through some things that I had been struggling with for months. During our chat, I picked up a plastic juice bottle with my hook and took a drink. It was a thin bottle with a wide neck, so I grabbed it near the bottom so it wouldn’t crush. After I set it down, he reached over and picked it up with his hook and said, “I never thought of holding one of those at the bottom like that so it doesn’t crush.” So you see, no matter how far along we are in our learning process, there can still be new revelations. Shortly after my encounter with the man at the diner, I heard about the ACA’s National Peer Network. I called and scheduled a peer visit and ultimately became a certified peer visitor in 2007. It has been a wonderful experience, full of countless tips both given and received.

Attending the ACA’s National Conference is another way to meet other people with upper-limb differences. This year at the 2009 National Conference in Atlanta, we had a record number of attendees who were missing part of one or both of their upper limbs. It was an extraordinary opportunity to sit through educational sessions, share our experiences with our peers and examine the latest prosthetic components and adaptive devices on display in the exhibit hall. We had sessions titled “Upper-Extremity Rehabilitation Techniques,” “Adjustment and Living Well With Upper-Extremity Limb Loss,” “Upper-Extremity Tips and Solutions” and an “Upper-Extremity Technology Symposium.” The sessions were hosted by members of the ACA’s new Upper Limb Loss Advisory Council in a forum that allowed for plenty of interaction between the presenters and attendees. I hosted the “Upper-Extremity Tips and Solutions” session. We had a 3-hour time period but we could have gone on for days. We discussed the things that work for us in the kitchen, the bathroom, at work, in the car and in many other areas of our lives. Within the group, we were able to offer tips and solutions for nearly every question that was asked, from how to button a shirt, drive a car or use a computer mouse, to which device will work best when mountain biking.

Use the resources available to you and never stop searching for answers. People often have very low expectations regarding the abilities of people with upper-limb loss. I have learned that it is possible to adapt and thrive even without an owner’s manual.