

Support

Being an advocate for yourself and others

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A spinal cord injury changed my life. But about a year after my accident, my wife and I were invited to join some young friends at their group home for an evening meal. They went to a lot of work getting my power chair around fences, over rough ground, and into their dining room.

After having a fine meal with our 15 friends, we began to talk more earnestly about how they were coping with their daily difficulties, some of which were addiction and mental illness. I didn't see it coming, but they then turned the table and asked me how I was coping with my new life.



To my friends, I was the same as I had been before my accident. My mind had difficulty trying to truly grasp what they had told me. To them, I was still "me."

So, I listed several things that I missed: bike riding, dancing, backpacking, playing guitar, and woodworking in my garage – all things of normal mobility. When I finished my list of laments, they told me that they had never known me in any of those ways, and to them I was the same as I had been before my accident.

I was the same! My mind had difficulty trying to truly grasp what they had told me. To them, I was still “me.”

I will never forget their gift to me. I was still a friend – and a real person – still valued in their eyes. I left there that evening more valued even in my own eyes.

May friends always bless us with the truths of their insights.

~ Patient Advisor

First Steps: What You Need to Know Right Now

- Understand that you must advocate for yourself. Others will not do this unless you ask.
- Make sure that you pick someone as your advocate, even though you may not need them. Going through this process will give you comfort in knowing there is someone who will help if and when you need it.
- A hospital stay is often very stressful. Because of your injury or illness, you may not have the energy or be able to gather all the information you need. Know that there are many individuals and resources that can support you. Start learning now how to better advocate for yourself so that you can ensure your needs are met.
- As a patient, you have certain rights and responsibilities. Knowing them will help improve your care now and in the future. Ask your nurse for a copy of the UWMC brochure “Information About Your Healthcare,” or look for a copy in your Discharge Binder.
- A trusted person can serve as your legal advocate, if needed. This person may act on your behalf and represent you in

legal, financial, and medical decisions. Start thinking about the right person to serve as your advocate in these ways.

Next Steps: What You Need to Know Long-term

There are many issues to consider when thinking about how to better advocate for yourself (or a friend or family member).

Of course, you will learn about your current health concerns during your inpatient stay. But, there are other issues related to your care and long-term health that also are important to learn about. These include:

- Scheduling your follow-up outpatient care
- Managing your medicines and treatments
- Making sure your needs are met with caregivers or long-term care facility staff

The U.S. government requires every state to have an *ombudsman* (long-term care advocate) to help people who have concerns about long-term care facilities. Read more about the ombudsman on pages 39 and 40 of this section.

Being an Advocate for Yourself and Others

You most likely have many new needs because of your condition. You now must attend to those needs while also navigating the healthcare system and interacting with the many members of your healthcare team. This can be overwhelming at times.

Learning how to speak in support of yourself or someone you care about is a very important part of maintaining your health and well-being. It is important that you understand your new health needs and how to use the resources that are available to you. This knowledge will help reduce stress and allow you to take a more proactive role in your healthcare.

An **advocate** is someone who can speak or act on your behalf. Having an advocate can be reassuring, and often works better than trying to handle all your needs by yourself. Some people may have someone in their life who knows when to step in.

But don't assume that a certain person will advocate for you. Make sure to ask them and talk about what you might need them to do.

Whether you are an advocate for someone else or for yourself, here are some skills to develop:

- **Listening and speaking.** Learn how to clearly communicate with your care team and family members. Write or speak in a way that is easy for others to understand.
- **Organization.** You will receive a lot of new information. Find ways to keep all of that information organized so that you can find it when needed. You, a supportive friend, or a family member will want to:
 - Keep a calendar of events and appointments
 - Organize and keep track of your health history, medicines, and other important information
 - Use a binder, file folder, or a folder on your computer to organize your records.
- **Willingness.** Managing all the aspects of your care may seem overwhelming at first. But, developing the willingness to do this will help you feel empowered and make sure your needs are met.
- **Being assertive and proactive.** Learn how to act in your best interest and speak up for your wants and needs. This is a vital part in maintaining your health, especially after you leave the hospital. Stay on top of your healthcare needs.
- **Expertise.** You can learn from both positive and negative experiences. Both will help you become an expert on how to deal with your care and will serve you well in the long run.

There also may be other skills that are helpful for an advocate to have. You may also want to be sure your advocate knows your medical history and has a flexible work schedule.

Roles for Advocates

Here are some tasks that either you or your advocate may do:

Make Contact Information Lists

Develop 2 contact lists. One is a list of your healthcare providers and insurance contacts. The other is a list of friends and family. Make a back-up copy of these lists.

The provider/insurance contacts list might include:

- Names, phone numbers, email addresses, text numbers, fax numbers, and addresses of your doctors, therapists, hospital(s), the hospital's financial counseling office, pharmacy (including refill lines/fax numbers), medical equipment supplier, insurance company, and any other person or service related to your care.
- The name and extension number of a contact person at the different care facilities and businesses, especially someone who has been helpful to you.
- Email addresses, if this way of communicating works for you and others.
- Your doctors' specialties and which illness or symptom they are treating.
- Records of service dates. Be sure to include the first date of service, and the last date of service if you are no longer using that provider or service.

Your list of family and friends might include:

- Names, addresses, email addresses, text and phone numbers, including home, work, cell, and fax numbers
- Notes about work schedules
- Phone tree and/or email address list
- Priority list of who should be contacted in case of an emergency or unexpected development
- Best time of day and method to contact each person

Here are some tips from other patients on creating contact lists:

- Create a contact list in your cell phone.
- Use a 1-page, clear plastic business card holder. Create cards for contacts who do not have printed cards.
- Type up your list on a computer and save the file. Print out a copy so it is handy when you need it.
- There are many apps that can help you organize this information and keep it on your phone. One example is the ICE (In Case of Emergency).

Make Phone Calls

You or your advocate will likely have to make many phone calls as part of your care. There are low-cost or free ways to make these calls. Two of these are:

- **Lifeline Free Cell Phone Program.** This government program provides discounts on monthly phone service for eligible consumers. If you use a landline, ask your phone company about discounts.
- **Google Voice, Skype, or another free internet calling services.** These allow you to use your computer to make calls.

Create a Medical History Timeline

It will be helpful to create your own medical history card or sheet. You or your advocate can create this timeline. It can have more information than your official medical chart.

Here are the items we suggest you put on your timeline:

- Your name.
- Date of birth.
- Basic insurance information and numbers, with space to write down preferred provider limitations, deductible levels, stop-loss policies, dollar allowances for inpatient rehab, length-of-stay limits, home healthcare coverage, and medical equipment coverage.

- Hospital information, such as your U-card number.
- Allergies to food and/or medicine.
- Health history (your own and your family medical history), including health habits, past illnesses, chronic illnesses, surgeries and outcomes, up to your present condition. When possible, include past doctors, dates of surgeries or hospital stays, medicines taken, and other treatments.
- Many providers also want to know your biological family's health history. They may ask if certain family members are still living, and if so, whether or not they have certain illnesses. Also, if a family member is no longer living, they will ask about the cause of death.
- Include the list of medicines as described below.

Make a List of Your Medicines

Keep an up-to-date list of the medicines you take. UWMC can give you a free medicine record card. Ask your nurse for one. You can also create your own medicine list with the help of MyChart. You can submit changes to your medicine through your MyChart page, including changes to non-prescription medicines.

You may want to keep this list by the phone and in your cellphone in case you have an emergency and you need to call 911. The items we suggest you put on this list include:

- Your name.
- The name of the medicine.
- The doctor or provider who prescribed the medicine.
- What the medicine is for.
- The dose of medicine you take. Some people also like to write down how and when the medicine is taken.
- Some patients and caregivers like to write down what the medicine looks like (for example, "little pink pill" or "big white oval pill").

Ask your doctor if you should include nonprescription medicines, vitamins, supplements, and herbal remedies on this list. Since these items can interact with other medicines you take, most doctors want to know everything you are taking.

It is also important that you:

- Always talk with your doctor before you start taking any new supplements or medicines.
- Update your card or list when you stop taking a medicine, when you start taking others, and when your dose changes.

Help with Medical Insurance Issues

You may want to consider having your advocate handle your medical insurance issues. Or, your advocate may be able to help you problem-solve.

- Be sure to include health insurance contact numbers on one of your contact information lists.
- You may also want to make a copy of your insurance card in case your original is lost.
- Most insurance companies provide a booklet on benefits. Keep this booklet in your files. Check to find out if the same information is on their website. If it is, it will be easy to check for updates online. Plan to check for updates at set times so that you always have the most current information.
- Call customer service at your insurance company if you need a better explanation of a benefit or a process related to your coverage. It is OK to ask them to send you the information they tell you in writing for future reference. Write down the name of the customer service agent who helped you and the date of your phone call.
- Many insurance companies offer **mail-in** pharmacy services, with lower co-payments or costs than using a traditional pharmacy.

Take Notes or Record Conversations with Care Team

It is hard to recall all of the information you receive during a visit with a healthcare provider. You can ask your advocate to take notes when you talk with a member of your care team. Or, your advocate might want to use a tape or digital recorder. Notes or a recording can be very helpful later. You can also access notes from your providers with MyChart.

Always date your communications in case you need this information later. Your advocate could also help you write down questions you have before you visit with care providers.

Legal and Other Appointed Advocates

You may want to have an advocate who helps only with legal issues. Legal documents can be prepared to help your legal advocate or advocates in other roles.

A power of attorney is a legal document in which you name another person to act for you. The person you name is your *agent* and you become the *principal*.

Many people do not know that an *ordinary* power of attorney is no longer in effect if you become incapacitated through illness or accident. If you want your agent to be able to act for you even if you are incapacitated, you must prepare legal documents giving them *durable* power of attorney.

While you are in the hospital, social work can provide forms and arrange for Notary Public for Power of Attorney forms. Your durable power of attorney may:

- Use your money to pay bills
- Contract home nursing services for your benefit
- Make basic healthcare decisions for you

Long-term Care Advocate

A long-term care advocate is called an *ombudsman*. By law, each state must have an ombudsman to help people who have concerns about long-term care facilities. Residents and their

loved ones can share their complaints to the ombudsman and have their concerns addressed so that they can live their lives with dignity and respect.

You can find a list of regional ombudsmen in Washington state at www.ltcop.org. The site includes emails and phone numbers (including toll-free numbers). To contact an ombudsman in another state, ask your rehab psychologist for help.

Please note that the Rehab Unit at UWMC is not considered a long-term care facility.

Caregivers

A caregiver may be your main support if you have a higher level of injury or illness. A caregiver can increase your ability to function and improve your quality of life.

Managing caregivers is like running a small home business with an employer and employee(s). As the employer, you seek good help and personalized care. You are also responsible to respect, guide, clearly direct, and pay the employee in compliance with your working agreement.

The employee has the right to be treated respectfully in a safe working environment. If you hire a caregiver directly, you manage that person. If you hire through an agency, then you “manage” the agency managers and the person working for you in your home.

If you hire a caregiver on your own, you are responsible for all legal requirements such as paying social security and withholding taxes. You’ll need to manage the payment source(s), deal with interviewing, hiring, training, and staffing, and develop policies for dismissal and turnover, emergency coverage, and back-up help.

See “Care After Discharge,” starting on page 49, to learn more about hiring and working with caregivers.

Others in Support Roles

Based on your care and personal needs, there may be others who serve in a support or advocate role for you. Your support needs may change over time. Be sure to speak up about what you need, from whom, and by when.

If needed, work on accepting support when it is offered and declining it graciously when the offer or the timing of the support is not right or not needed.

Notes
