

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.

So, I listed several things that I missed: bike riding, dancing, backpacking, playing guitar, and woodworking in my



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."

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 Advocates Need to Know Right Now

- A hospital stay is often very stressful. Because of your injury or illness, you may not have the energy or be able to gather the information you need. The first step is knowing that many individuals and resources are available to support you. It is also important to start learning 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 Health Care*, 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 Advocates 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). This section of your manual will explain many of these issues.

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 page 41 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 health care system and interacting with many different members of your health care 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 health care.

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

- **Listening and speaking** – It is important to learn how to clearly communicate information between you, your care team, and family members, as well as write or speak in a way that is easy for others to understand.
- **Organization** – You will receive a lot of new information. It is important to keep all of that information organized so

that you can find it when you need it. 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
- **Willingness** – Managing all the aspects of your care may seem overwhelming at first. But, developing the willingness to do this but will help you feel empowered and able to 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 health care 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. And, you may want to be sure your advocate knows your medical history and has a flexible work schedule.

Roles for Advocates

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

Make Contact Information Lists

Develop 2 contact lists. One is a list of your health care providers and insurance contacts. The other is a list of friends and family. No matter what information you include, make a back-up copy of your contact lists.

The provider/insurance contacts list might include:

- Names, phone 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, 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 your contact lists:

- Use a one-page, clear plastic business card holder and insert cards. Create cards for people and service providers who do not have printed cards. There is a sample one-page business card holder in your *Discharge Binder*.
- Type up your list on a computer and save the file. Print out a copy so it is handy when you need it.

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:

- Getting a discounted landline from your phone company
- Using a free Internet calling service such as Google Voice or Skype, which you can use to make calls using your computer

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 care 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 about your biological family's medical history. Often, they ask if certain family members are still living, and if so, whether or not they have chronic illnesses such as high blood pressure, glaucoma, multiple sclerosis, heart disease, or cancer. 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. Or, you can create your own list.

You may want to keep this list by the phone in case you have an emergency and you need to call 9-1-1. 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 over-the-counter 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 over-the-counter 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

There is a complete review of medical insurance issues on pages 3 and 4 in “Entry to UWMC.” 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 medical 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 a customer service representative 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. Keep the name of the customer service representative 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 Members

It is common for patients not to recall all of the information given to them during a visit with a health care 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.

Your advocate might also help you write down questions you have before you visit with health 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.

An easy-to-complete form to name a durable power of attorney is in the booklet “Information About Your Health Care,” which you will find in your *Discharge Binder*.

Your durable power of attorney may:

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

Long-term Care Advocate

A long-term care advocate is called an *ombudsman*. Each state is legally required to have an ombudsman to help people who have concerns about long-term care facilities. Residents and their loved ones can voice their complaints to the ombudsman and have their concerns addressed so that residents can live their lives with dignity and respect.

A list of regional ombudsmen in Washington state is online at www.ltcop.org. The website includes phone numbers (including toll-free numbers) and email contact information. 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) and deal with all related personnel issues, such as interviewing, hiring, training, and staffing, and develop policies for dismissal and turnover, emergency coverage, and back-up help.

See "Care After Discharge," 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 at being able to accept support when it is offered and to decline it graciously when the offer or the timing of the support is not right or not needed.

Questions?

Your questions are important. Talk to your doctor, nurse, or other health care provider if you have questions or concerns.

While you are a patient on Inpatient Rehab, call:
206-598-4800

After discharge, call your primary care provider or UWMC's Rehabilitation Clinic: 206-598-4295