UW Medicine UNIVERSITY OF WASHINGTON MEDICAL CENTER

Care After Discharge

Helpful tips

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From your first day in the hospital, think about your transition to home.



You will most likely keep working on your rehab goals after discharge.

Let us help you refer all that you learn to how it will work at home, in your community, and in your workplace.

Always think of the Inpatient Rehab Unit as a bridge – and we will travel that bridge with you.

~ UWMC Staff

Preparing for Discharge

Your time on the Inpatient Rehab Unit is spent preparing for discharge. Unlike other types of hospital stays, leaving inpatient rehab does not mean you're done with your rehabilitation. You will most likely keep working on your rehab goals after discharge.

Rehab staff will work with you and do all they can to prepare you for discharge. Their role is to make sure you learn the skills you need to make a successful transition to home. To help the people who will care for you after discharge, use a checklist to keep track of the information you receive. Also record who received the information: you, your advocate, or a caregiver. You can find a sample Discharge Checklist in the "Helpful Resources" section of this manual.

From Rehab Staff

The rehab team is here to help you make a smooth transition between your hospital stay and going home. We want to help you be as safe and independent as you can be. We will work with you to meet your goals.

Tips from Patient Advisors

- Your care team will talk a lot about discharge goals. An
 important question to ask yourself is: "What are the qualityof-life elements I want to preserve?" For example, if you love
 swimming, enjoying the water is the quality. One discharge
 goal would be to have skills that will help you still do that.
- Go over your "normal" activities for the day and think about the changes that will need to occur so you can do these things. Review this list with your caregiver and your care team and add their suggestions.
- Discharge and the transition to home can be very stressful. Be patient with yourself and with those who are helping you, and thank them for their help.
- Remember how the first few days in rehab were? Going home is a lot like that. Know that it is going to get easier over time.
- Be clear about the discharge plan and agree about what can be done to meet your needs.
- If you will need to inject medicines, take intravenous (IV)
 medicines, clean medical equipment, or have other technical
 care needs once you go home, practice these activities many
 times before you go home. Show your care team that you
 know how to do each activity. Doing this will help you be
 more at ease doing these activities at home.

- It is better to plan to have "too much" help after discharge than "just enough." It is easier to cut back than to add. Sometimes we feel embarrassed to ask for help. We may need help with something private or painful, which makes us feel anxious about asking. Or we might say to ourselves, "No problem, I won't need help," but when we get home, we very much need the help and it is not there. So please, plan to have too much help.
- You may want to call on many people, groups, and agencies for support. Who are the family members or loved ones who can help? What can they do? What support can your community provide? Are there support groups? Where can you find other information – on the internet, or other places? (See "Helpful Resources" for ideas and support).
- Identify what caregivers you need and their roles. Your rehab team can help you figure this out. Start talking about this early in your stay on the Rehab Unit. This will help you avoid having to make last-minute decisions.
- Remember, your rehab routine may change over time and your needs will change, too. Think about your needs early in your stay. They may include transportation, (wheelchair access), ramps, bed height, strength of the person to help you, and more.
- It is very important to have a "go-to" person, a personal advocate, who you can call for help when needed. As you get settled at home, you won't have the people around you in the way you did in the hospital. You will need someone who can help.
- Your care team will work with you to try to identify who can help you after discharge. Your long-term needs may become clearer during your hospital stay. Sometimes it turns out that because of your care needs, the person who you thought could help will not be able to do so, or not at the level needed. If this happens, you will need a "plan B."

- After discharge, you will be interacting more often with people you do not know. When you need help from someone, try asking this way:
 - First describe why you need help, such as "I can't reach ..." or, "I can't stand up ..."
 - Then say, "Please help me to ..."
- If any information you are given in rehab is not clear, be sure you understand it *before* discharge.

Caregivers

What You Need to Know Right Now

A big part of coming to terms with an injury or disability is accepting your physical limits. You may have to rely on help from others. It may be hard to balance keeping your independence and dignity with needing help from others.

Caregivers can improve the quality of your life by increasing your ability to function and your independence. Assess your abilities and needs. Ask yourself what you can do for yourself and what you need a caregiver to do.

Also consider your safety and how long it will take you to do a task yourself. Caregivers can help you with many tasks, including bathing, bowel and bladder care, getting dressed, and filling medi-sets with medicines. It may be helpful to create a personal handbook that you can give to your caregivers with information on how to best help you.

Family Caregivers

You may be wondering if a family member should be your caregiver. Some people choose a family caregiver because of finances or not being able to hire a caregiver before discharge.

If a family member is your caregiver, they must juggle their family role with the caregiver role. It will be important for everyone to understand the caregiver's dual responsibilities.

Many emotional and communication issues will come up when a loved one is your caregiver. This can lead to tension and blurred relationship boundaries. Think about the issues that are likely to arise. Talk with your loved one about these issues ahead of time. Talk about them again when they do come up.

Having a family member as your caregiver can work well when there is open communication and respect. If a partner is going to become your caregiver, think about how all areas of your relationship will be affected. Self-esteem and dignity for both you and your caregiver are important.

Good communication can help ensure that you are not asking for too much or too little help. Also be aware of what can happen if you "lash out" at those closest to you. It may help to do some research about how to communicate when you are feeling angry or frustrated.

Hiring a Caregiver

If you need to hire a caregiver, there are many emotional, legal, and practical issues to think about first. The "Helpful Resources" section provides tips from patient advisors and sample forms.

It can be emotionally challenging to hire a caregiver, but it may be your best solution. Before hiring anyone, it is wise to learn how to screen, hire, train, and develop a working relationship with someone. Since you will be an employer, there are also many legal and tax issues to learn about.

At times you may have problems with caregivers. Be assured that in almost all cases, there are safe and effective solutions.

What You Need to Know Long-term

Whether your caregiver is a family member or you hire someone, always have a back-up plan. Know what you will do when your caregiver takes time off or there are emergency situations.

Over time, you will learn how to manage caregivers and how to keep boundaries in place. It is a learning process, so be patient with yourself. Here are some suggestions to keep in mind:

- **Think like a business.** Managing caregivers is like running a business. You must learn what employment situation works best for you, legally and financially. You will also need to think about:
 - Employer taxes (you will need to apply for a tax ID number)
 - Worker's compensation-type insurance
 - Homeowner's or renter's insurance for personal injury
- **Stay organized.** Being organized will make it easier when there are changes and you need to use a back-up plan, hire a new employee, or ask a loved one to fill in short-term.
- **Support your caregivers.** Do what you can to make sure your caregivers are taking care of themselves. They will feel stress and will need your consideration and support. This includes giving them time off and having fill-in help. Be alert to "employee burnout," especially with caregivers who work 24 hours a day, are "live-in," or who work 7 days a week.

Before Hiring a Caregiver

If you decide to hire a caregiver, think about what their duties will be, such as:

- Work days and hours
- Your personal care, healthcare, and emotional needs
- Household care needs

Also, know what qualities are important to you. You may want a caregiver who has a positive attitude, is reliable and honest, and has experience with caregiving. You may want someone who is a nonsmoker, clean, and lives nearby.

You will also need to make certain decisions:

 Do you want to hire someone yourself or use an agency? This may depend on your insurance coverage or other factors. Hiring a caregiver on your own may be less costly, but you will need to screen applicants and plan for back-up care if your caregiver is ill.

- Do you want to use your own contact information in ads?
- **Do you want to interview in person?** Will interviews be at your home or in a public place? Or will someone you trust do the first round of interviews? If you will do the interview in person, do you want someone you know to be there with you?
- If you interview by phone or Zoom, do you want to use your own phone or computer to screen and interview applicants?

Advertising

Placing ads can be frustrating. Many people may respond, but hardly anyone may call. Do not be discouraged and do not "settle" or compromise on the important qualities you need in a caregiver. Also, keep in mind that some people with less experience can be fast learners and great caregivers.

A good ad can be brief. If you start the ad with the word "Aide," your ad will appear near the top of the list in the classifieds.

Here's an example of an ad to use when seeking an aide to work weekday mornings, who has their own car, and speaks English. This ad includes the general area and a phone number.

AIDE – Mon-Fri a.m., car, English. North Seattle. 206.XXX.XXXX

Tips:

- Placing an ad on a website such as *craigslist.com* works well for some people.
- You can also post flyers at local community colleges and places of worship, or use word of mouth.

Sample Forms

There are sample forms in the "Helpful Resources" section of this *Rehab and Beyond* manual to help you with the hiring process:

- The **sample "Help Wanted" ad** (page 96) summarizes the job and the kind of person you're looking for. It can be posted at places such as local community colleges and places of worship. It can also be used as a job description during an interview.
- The **caregiver application form** (pages 97 to 100) has questions that will help you get to know the applicant's personality, experience, work ethic, and possible conflicts. These questions can help reduce surprises after hiring someone.
- The **applicant release form** (page 100) gives written permission to contact references and previous employers. Many employers require this release form before they will talk with you about the applicant.

When you receive calls from applicants:

- **Refer to your job description flyer.** Have your application form ready. Screen for the most important issues first.
- **Trust your instincts.** Pay attention to your own response to the applicant. Is this someone you would like to share your living space with?
- Verify the applicant's experience and references.
 Background checks are affordable and often can be done in 1 day.

Tips:

- Think twice about hiring a caregiver who needs to bring their children to work. They might need to focus more time and attention on their children than on you.
- Students and older workers can be very good caregivers.

Working with Your Caregiver

- You will be directing your caregivers in what tasks you need help with. Some people find it helpful to have a detailed "Daily Routine" list with times to keep both their caregivers and themselves on track.
- Your caregivers can help you with tasks other than personal care, such as laundry, fixing meals, or cleaning. It may be helpful to have a caregiver checklist that includes household tasks that need to be done on a daily or weekly basis.
- Tell your caregiver that you are open to talking about problems. Ask your caregiver for suggestions when issues arise. Make sure they know their opinion counts.
- When problems come up, handle them right away. If you use an agency, work through the agency to solve the issue.
- If you are the employer:
 - Talk about problems and resolve them as soon as they come up. Do not let a small issue turn into a bigger one.
 - Tell your caregiver your concerns, both verbally and in writing. Even if you feel that doing this is too business-like, remember that this working relationship is the most important one you have. Your quality of life depends on it.
 - Agree on what changes need to be made, and ask the caregiver to tell you those changes in their own words.
- When working with your caregiver:
 - Try using humor.
 - Do your best to create a pleasant working environment.
 - Keep the relationship professional.
 - Keep your personal and financial papers out of sight.
 - Have private areas of your home that are off-limits to your caregiver.
- Be alert if a caregiver:
 - Asks for advances or loans.

- Causes health and safety risks due to carelessness.
- Is late for work, does not show up, does sloppy work, or does not finish work.
- Has behaviors that bother you, such as smoking, talking on the phone or texting a lot, or watching too much TV.
- Have a written policy for firing a caregiver. Firing someone is hard to do. If you need to fire someone, ask a friend or family member to be there if you feel threatened. Be calm, assertive, and direct.
- When a caregiver leaves your employment, make sure they return your keys and other personal property. Change your locks if you feel even a little uneasy.
- Accept that no one employee will be with you forever. Use what you have learned to improve your working relationship with future caregivers.

"It's normal to be concerned about your discharge. It's a little like going home with a new baby. You will be in a new role, one that you haven't been in before. If you have questions or concerns before you go or after you leave the Rehab Unit – speak up."

~ Patient Advisor

Questions?

Your questions are important. Talk with your doctor, nurse, or other healthcare 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