Rehab and Beyond

Resources to maximize your potential

The Montlake Bridge, just south of University of Washington Medical Center - Montlake campus in Seattle.
The Bridge Builder
By Will Allen Dromgoole

An old man, going a lone highway,
Came, at the evening, cold and gray,
To a chasm, vast, and deep, and wide,
Through which was flowing a sullen tide.

The old man crossed in the twilight dim;
The sullen stream had no fears for him;
But he turned, when safe on the other side,
And built a bridge to span the tide.

“Old man,” said a fellow pilgrim, near,
“You are wasting strength with building here;
Your journey will end with the ending day;
You never again must pass this way;
You have crossed the chasm, deep and wide –
Why build you a bridge at the eventide?”

The builder lifted his old gray head:
“Good friend, in the path I have come,” he said,
“There followeth after me today,
A youth, whose feet must pass this way.

“This chasm, that has been naught to me,
To that fair-haired youth may a pitfall be.
He, too, must cross in the twilight dim;
Good friend, I am building the bridge for him.”
A Note to Patients and Their Loved Ones

At UWMC Rehabilitation Services, our main goals are to:

- Provide safe, high-quality medical care to our patients and support for their families.
- Make your hospital stay comfortable.
- Partner with you to help you recover as much of your ability to function as possible.

A team of doctors, nurses, allied health professionals, and other support staff will work with you and your trusted loved ones. Together, we will create a team that focuses on your care and the support you need.

With your input and guidance, our team is here to provide you and your family the best care possible. Please let us know how we can help. Thank you for choosing UWMC for your healthcare needs.

Your Rehab and Beyond Manual

This Rehab and Beyond manual was written by a team of patients and staff who are serving as advisors on the UWMC Rehabilitation Services Patient and Family Advisory Council. They bring many years of personal experience to this manual, and hope that it provides helpful support for the journey that lies ahead.

If you have ideas or suggestions for future editions of this manual, please send them to:

Rehabilitation Services Advisory Council
c/o Patient and Family Centered Care Program
1959 N.E. Pacific St., Box 359420
Seattle, WA 98195
Email: pfcc@uw.edu
Patient and Family Centered Care

University of Washington Medical Center (UWMC) provides healthcare using an approach called Patient and Family Centered Care (PFCC). PFCC invites patients to be as involved in their own healthcare as they want to be.

PFCC also actively involves patients, families, and staff as partners in developing programs and policies and influencing day-to-day interactions in the medical center. Some of its core concepts are communication, information sharing, choices, respect, partnership, and the understanding that the presence of family is a strength, not an inconvenience.

Patient and Family Centered Care leads to better health outcomes, wiser allocation of resources, and greater employee, patient, and family satisfaction. It is simply the right thing to do.

Without UWMC’s practice of Patient and Family Centered Care, Rehab and Beyond would not have been written. A dedicated team of patients, family members, and staff produced this manual. All of these team members added insights, information, and valuable input based on their own expertise and experience.

For more information about Patient and Family Centered Care at UWMC, please contact:

Andrea Dotson
Manager, UWMC Patient and Family Centered Care
206.598.7448
pfcc@uw.edu

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 the Inpatient Rehab Unit, call:
206.598.4800

After discharge, call your primary care provider or UWMC’s Rehabilitation Clinic:
206.598.4295
# Table of Contents

**Rehab and Beyond**

About *Rehab and Beyond* ................................................................. ix

## Entry to UWMC ................................................................. 1

- When You Are Admitted ................................................................. 1
- Stages of Care .................................................................................. 2
- Who can help me and my family with this entry process? ........... 3
- What questions should I ask? .......................................................... 3

## About the Rehab Unit .......................................................... 5

- Rehab Unit Layout ........................................................................ 6
- Your Room ....................................................................................... 6
- Meals and Food ................................................................................ 8
- Visitors ............................................................................................ 9
- Smoking .......................................................................................... 9

## UWMC Services and Facilities ........................................... 11

- Food and Drinks ............................................................................. 11
- Maps and Finding Your Way .......................................................... 12
- Transportation and Parking ............................................................ 12
- UWMC Pharmacy .......................................................................... 13
- Business Services .......................................................................... 13
- Other Resources ............................................................................ 13
- Using a Webpage to Stay in Touch .................................................. 14

## Your Care Team ................................................................. 15

- You: The Patient ............................................................................ 15
- Medical Staff ................................................................................ 16
- Nursing Staff ................................................................................ 16
- Allied Health Professionals ............................................................ 17
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support Staff</td>
<td>20</td>
</tr>
<tr>
<td>Peer Mentors for People with Spinal Cord Injury</td>
<td>21</td>
</tr>
<tr>
<td>Caregivers</td>
<td>22</td>
</tr>
<tr>
<td>Advocates</td>
<td>22</td>
</tr>
<tr>
<td>Others Who Can Support You</td>
<td>22</td>
</tr>
<tr>
<td>Your Plan of Care and Setting Goals</td>
<td>23</td>
</tr>
<tr>
<td>Steps to Develop a Plan of Care</td>
<td>24</td>
</tr>
<tr>
<td>Your Plan of Care</td>
<td>24</td>
</tr>
<tr>
<td>Tips on Setting Goals</td>
<td>25</td>
</tr>
<tr>
<td>Being a Partner in Planning Your Care</td>
<td>26</td>
</tr>
<tr>
<td>Change as a Part of Life</td>
<td>27</td>
</tr>
<tr>
<td>Support</td>
<td>31</td>
</tr>
<tr>
<td>First Steps: What You Need to Know Right Now</td>
<td>32</td>
</tr>
<tr>
<td>Next Steps: What You Need to Know Long-term</td>
<td>33</td>
</tr>
<tr>
<td>Being an Advocate for Yourself and Others</td>
<td>33</td>
</tr>
<tr>
<td>Roles for Advocates</td>
<td>35</td>
</tr>
<tr>
<td>Legal and Other Appointed Advocates</td>
<td>39</td>
</tr>
<tr>
<td>Long-term Care Advocate</td>
<td>39</td>
</tr>
<tr>
<td>Caregivers</td>
<td>40</td>
</tr>
<tr>
<td>Others in Support Roles</td>
<td>41</td>
</tr>
<tr>
<td>Financial Concerns</td>
<td>43</td>
</tr>
<tr>
<td>Planning Ahead</td>
<td>43</td>
</tr>
<tr>
<td>UWMC Financial Counseling</td>
<td>44</td>
</tr>
<tr>
<td>Check Your Health Insurance Plan</td>
<td>44</td>
</tr>
<tr>
<td>Public Health Insurance Plans</td>
<td>46</td>
</tr>
<tr>
<td>Disability Income Insurance</td>
<td>47</td>
</tr>
<tr>
<td>Other Options</td>
<td>48</td>
</tr>
<tr>
<td>Care After Discharge</td>
<td>49</td>
</tr>
<tr>
<td>Preparing for Discharge</td>
<td>49</td>
</tr>
<tr>
<td>From Rehab Staff</td>
<td>50</td>
</tr>
<tr>
<td>Section</td>
<td>Page</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>Tips from Patient Advisors</td>
<td>50</td>
</tr>
<tr>
<td>Caregivers</td>
<td>52</td>
</tr>
<tr>
<td>Before Hiring a Caregiver</td>
<td>54</td>
</tr>
<tr>
<td>Working with Your Caregiver</td>
<td>57</td>
</tr>
<tr>
<td><strong>Managing Caregivers</strong></td>
<td>59</td>
</tr>
<tr>
<td>Personal Boundaries and Caregivers</td>
<td>59</td>
</tr>
<tr>
<td>Caring for Your Caregivers</td>
<td>62</td>
</tr>
<tr>
<td>Thoughts About Caregivers</td>
<td>62</td>
</tr>
<tr>
<td><strong>Self-care</strong></td>
<td>67</td>
</tr>
<tr>
<td>Good Habits</td>
<td>67</td>
</tr>
<tr>
<td>Planning Your Day</td>
<td>68</td>
</tr>
<tr>
<td>Managing Fatigue</td>
<td>69</td>
</tr>
<tr>
<td>Getting Help</td>
<td>70</td>
</tr>
<tr>
<td>Supplies</td>
<td>71</td>
</tr>
<tr>
<td>Staying Current</td>
<td>71</td>
</tr>
<tr>
<td><strong>Eating to Heal</strong></td>
<td>73</td>
</tr>
<tr>
<td>A Balanced, Healthy Diet</td>
<td>73</td>
</tr>
<tr>
<td>If Your Appetite Is Low</td>
<td>74</td>
</tr>
<tr>
<td>Plan Ahead</td>
<td>75</td>
</tr>
<tr>
<td>Foods for Specific Health Issues</td>
<td>76</td>
</tr>
<tr>
<td>Food Safety</td>
<td>78</td>
</tr>
<tr>
<td><strong>Safety Concerns</strong></td>
<td>79</td>
</tr>
<tr>
<td>Home Safety</td>
<td>79</td>
</tr>
<tr>
<td>Fire Safety</td>
<td>77</td>
</tr>
<tr>
<td>Personal Safety</td>
<td>81</td>
</tr>
<tr>
<td>In Case of Emergency</td>
<td>83</td>
</tr>
<tr>
<td><strong>Follow-up</strong></td>
<td>85</td>
</tr>
<tr>
<td>What to Expect After Discharge</td>
<td>85</td>
</tr>
<tr>
<td>Your Outpatient Care Team</td>
<td>86</td>
</tr>
</tbody>
</table>
Coordinating Your Care ................................................................. 87
Requesting Your Medical Records ............................................... 88
Medicines (First Prescriptions and Refills) .................................... 88
Preventive Care: Staying Healthy Going Forward ...................... 89
Solving Problems After Discharge ................................................. 91

**Helpful Resources** ................................................................. 93

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>UWMC Patient Resources</td>
<td>94</td>
</tr>
<tr>
<td>Services in the Seattle Area</td>
<td>94</td>
</tr>
<tr>
<td>Independent and Supported Living Options</td>
<td>95</td>
</tr>
<tr>
<td>Modifying Your Home</td>
<td>96</td>
</tr>
<tr>
<td>Transportation</td>
<td>96</td>
</tr>
<tr>
<td>Becoming an Employer</td>
<td>98</td>
</tr>
<tr>
<td>Online Guides for Hiring and Managing Caregivers</td>
<td>100</td>
</tr>
<tr>
<td>Medicines (First Prescriptions and Refills)</td>
<td>88</td>
</tr>
<tr>
<td>Preventive Care: Staying Healthy Going Forward</td>
<td>89</td>
</tr>
<tr>
<td>Solving Problems After Discharge</td>
<td>91</td>
</tr>
<tr>
<td>Helpful Resources</td>
<td>93</td>
</tr>
</tbody>
</table>

**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 the Inpatient Rehab Unit, call: 206.598.4800

After discharge, call your primary care provider or UWMC’s Rehabilitation Clinic: 206.598.4295

© University of Washington Medical Center
Clinician Review: 10/2021
Reprints on Health Online: https://healthonline.washington.edu
About *Rehab and Beyond*

*How to use this manual*

**In this section:**
- What will I find in this manual?
- How is the manual set up?
- How might I use *Rehab and Beyond*?

I wish I had a resource like this manual when I was a patient here. I worked with other UWMC patients to make this manual happen. We have tried to include all of the things we wish we had been told. Or, maybe we were told, but we don’t remember.

When you are first on the Rehab Unit, there is so much to learn. It can be overwhelming. We created this manual so that you can find the section you need.

The main subjects in each section are listed on the first page. If you want to know about something and you can’t find the answer here, ask someone on the staff.

~ Patient Advisor
The authors of *Rehab and Beyond* wanted to create a manual that is helpful to you, your family, and others close to you as you face new challenges and a changed lifestyle. Some of the authors are patients who have been in inpatient rehab before you. Others are staff members on the unit and other departments at the medical center.

Like the old man in “The Bridge Builder,” the poem inside the front cover, inpatient rehab patients and their family members also must cross a “chasm.” Our chasm is not like the one in the poem, but it may be just as hard to cross.

Our hope is that this manual will serve as your “bridge” to your new life, both while you are in inpatient rehab and after you are discharged. It gives you information on the physical set-up of the unit, the staff, and what to expect during your stay. It also describes many resources you can access once you leave the hospital. These resources can help you with hiring caregivers, knowing about transportation and recreation options, supporting your personal relationships, and more.

We invite you to enter the challenging, compassionate, and technically competent world of inpatient rehab, to meet your rehabilitation team members, and to learn about the services we offer.

**What will I find in this manual?**

*Rehab and Beyond* is your reference manual. Sections include:

- Entry to UWMC
- About the Rehab Unit
- UWMC Services and Facilities
- Your Care Team
- Your Plan of Care and Setting Goals
- Support
- Financial Concerns
- Care After Discharge
• Managing Caregivers
• Self-care
• Eating to Heal
• Safety Concerns
• Follow-up
• Helpful Resources

How is the manual set up?

For this manual, we wanted to focus on the basics – the information we wish we had when we were inpatients. Each section includes short quotes from people who have received care or who are currently receiving care on UWMC’s Rehab Unit.

The front page of each section lists the topics covered in that section. Terms are defined when they appear. Tips from staff and patients are included in each section. We’ve also included “Notes” pages in various places for you to use as needed.

How might I use Rehab and Beyond?

Use your Rehab and Beyond manual in whatever way works best for you. You can read the manual from front to back, or you may want to turn to the section that is most likely to meet your current needs.

You may want to bring the manual with you to your clinic visits. Be sure to ask your doctors, nurses, or other caregivers if you need more detailed information than you find in Rehab and Beyond.
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 the Inpatient Rehab Unit, call: 206.598.4800

After discharge, call your primary care provider or UWMC’s Rehabilitation Clinic: 206.598.4295
Entry to UWMC

What to expect

In this section:
• When You Are Admitted
• Stages of Care
• Who can help me and my family with this process?
• What questions should I ask?

You will be asked for the same information many times – from the time you are admitted, throughout your course of treatment, up until the time you go home.

Be patient with this part of the process. And, try to keep the basic information somewhere where you can find it every time you need it.

~ Patient Advisor

When You Are Admitted

We will give you a great deal of information when you arrive. It is a lot to take in, whether you are already at UWMC and recently admitted to rehab, or you came from another hospital.
There is also a lot to do. You may need to fill out forms, get information from doctors, and have medical tests done. We may also need to assess your eligibility for various treatments. To help you cope with all this:

- Please know that you do not have to process everything at once. It is normal to be overwhelmed by the rehab approach to care and everything that happens during rehab. Most people find it works best just to take things a step at a time.
- Think about naming 1 person – a trusted family member or friend – for the care team to talk with when they have questions or concerns and you are not available or don’t feel up to talking.
- Feel free to ask questions about your injury or disease process, and about what to expect on the Rehab Unit. If there is anything that is explained or done that does not make sense to you, ask questions until you understand.
- You will need to keep track of and organize the large amount of information you receive during your stay. Find and use a system that works best for you.
- There are a lot of admission forms. When you are admitted, you will answer questions about your health history, have your vital signs checked, and answer many other questions, too. Your answers will help your care team start to create a plan of care for you.

### Stages of Care

This first stage of your care is called the **assessment phase**. From the beginning, you will be asked to think about your rehab goals: What do you want to accomplish so that you feel more independent?

We will encourage you to start putting together a supportive group of family and friends who can help you while you are in the Rehab Unit and after you leave the hospital. See “Your Plan of Care and Setting Goals,” starting on page 23 and “Support,” starting on page 31 for help with this step.
Who can help me and my family with this entry process?

Each person plans and seeks support in their own way. Most importantly, you must help with your recovery and rehab process. Take time to get clear about what you want.

It may not be easy to think clearly right now. That’s OK. Do the best you can and know that you can change your mind about what is important, what your goals are, and even about who can help you. (See “Support,” starting on page 31.)

One tip is to ask others for their “one best idea.” This decreases the amount of ideas you have to filter through. But, some people process best when they review a range of ideas.

For extra help, you may want to talk with these professionals:

- A **rehab psychologist** has years of experience helping patients in situations that are like yours. A rehab psychologist is trained to help you with this entire process.

- A **social worker** can help you with planning for discharge. (See “Care After Discharge,” starting on page 49.)

What questions should I ask?

It can be hard to know what questions to ask. It is OK to ask others what they think is important for you to know. It may help to brainstorm a list of topics, such as home care, support, transportation, and legal forms. We have tried to fill this *Rehab and Beyond* manual with a lot of the information you might need.

You might want to ask questions about:

- What to expect about your care and life on the Rehab Unit.

- Your disease process or injury and how it will affect you and your family.

- Anything you do not understand. This is how you can become an expert on your care and make the best decisions for you and your family.
• Resources from staff, former patients, insurance companies, and the internet to help your recovery.

• The ways information can be given. We want to give information in the way you prefer to receive it. Tell us if you learn best by:
  - Reading written materials,
  - Seeing videos or watching someone, or
  - Doing demonstrations

If you think of a question and cannot ask it right away, write it down, record it, or ask someone else to write it down for you. If you had a question and forgot to ask it, please ask later when you remember it.

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 the Inpatient Rehab Unit, call: 206.598.4800

After discharge, call your primary care provider or UWMC’s Rehabilitation Clinic: 206.598.4295
About the Rehab Unit

Helpful information

In this section:
- Rehab Unit Layout
- Your Room
- Meals and Food
- Visitors
- Smoking

Our time on the Rehab Unit is often an abrupt and often overwhelming change from our planned lives. As we yearn for full recovery or cure and a return to normal life, gains can seem painstakingly small and the effort exhausting. But each gain is valuable and each step forward furthers your progress.

Take heart that you are in one of the nation’s very best hospital-based rehab units. The doctors and staff are absolutely dedicated to helping you each and every day to maximize your recovery of daily activities. Through the sadness and the joy, work hard! Your time on 8-North will pass very quickly.

~ Patient Advisor

This section of Rehab and Beyond describes your room and the Rehab Unit. If you have questions about the unit, please ask your nurse or any member of your care team.
Rehab Unit Layout

The Rehab Unit is on the 8th floor of UWMC - Montlake. It is in the 8N (8-North) wing of the hospital, near the Pacific elevators.

The unit has 16 beds. The nurses’ station and main services are at the entrance to the unit. There are 2 bathrooms on the unit that are like bathrooms you would find in a house. One has a tub and shower stall and the other has a large walk-in shower. There is also a Laundry Room and a Patient and Family Lounge/Conference Room.

Your Room

Your room is set up for your comfort and safety, and to make it easy for your care team to help you.

- Your bed can be adjusted. Your nurse will teach you how to adjust your bed and bedside table so you are comfortable and safe.
- There are wall lights above the bed and a special ceiling light that your doctor or nurse may use.
- There is a bathroom in your room. There is an emergency call button/pull cord right next to the toilet.
- There is space in the room to store your personal items.
- Your room is cleaned every day.

Call Button

Use your call button to call for your nurse when you need help. When you push the call button, you may hear a nurse answer through the panel near the head of your bed.

The call button unit can be clipped close to you so that you can reach it easily. The unit includes controls for the TV so that you can change channels and adjust the volume.

If you cannot work the controls on the call button unit, ask someone on your care team about other options. We can change the controls to make them easier to use.
Heating and Cooling
If you are too hot or too cold, please tell your nurse. We can give you a fan or extra blankets.

Phone in Your Room
There is a phone for each bed in your room. To make local calls outside the hospital, enter 9 before entering the phone number.

We also have phones for patients with special needs. Ask your nurse if you need this kind of help.

Cell Phones
If you prefer, you may use your cell phone to make calls.

Internet
You can use your own smartphone, tablet, or laptop computer while you are on the Rehab Unit. Most areas of the hospital have free Wi-Fi access. To connect to the internet:
- Open your wireless device (such as laptop or smartphone).
- Choose the network called “Patients and Visitors.”
- Open your internet browser.
- Review our Terms and Conditions.

Entertainment
Your room has a TV mounted on the wall. Your call button unit has a TV channel changer and volume control. You can also use your own streaming or smart TV device.

Rehabilitation Gym
You will work with your therapists at the Rehab Gym. The gym is in the hospital, just a short distance away from 8N. Staff will help you get to and from the gym.

The gym has:
- Mat tables for you to lie or sit on to practice moving and doing your exercises
• Parallel bars and other equipment to help you with walking
• Weights, bikes, and other equipment to help you gain strength and endurance in your arms and legs
• Puzzles, games, small items, and other equipment to help you with fine motor coordination

Meals and Food

Meal Service
The hospital offers room-service meals to inpatients. Staff from Food and Nutrition Services will bring you a menu and explain how the service works. Your meals will be delivered to your room outside of your scheduled therapy times.

Please note that your medical needs may decide what foods you can and cannot eat.

Hospital Cafeteria
The cafeteria is called the Plaza Café. It is on the 1st floor of the hospital, near the Pacific elevators. It is open every day.

Espresso and Coffee
There are 3 Espresso stands in the hospital:
• Near the Gift Shop, 3rd floor, open weekdays and weekends
• In the rear of the Plaza Café, 1st floor, open weekdays
• In the Surgery Pavilion, 1st floor, open weekdays

You can also buy drip coffee in the Gift Shop on the 3rd floor.

Food from Home
If you want to bring food from home:
• Tell your patient services specialist (PSS), patient care technician (PCT), or nurse (RN).
• If you are on a special diet, your doctor will need to approve any foods brought from outside the hospital.
Visitors

Your family and friends are welcome to visit at any time, but we ask that they respect your therapy schedule. Visitors may be limited if you have a roommate or for your own health needs.

Hospital visitors need to wear an ID badge between 9:30 p.m. and 5:30 a.m. Your visitors can get their ID in the lobby on the 3rd floor.

Smoking

UWMC is a smoke-free and tobacco-free hospital. We are committed to a safe and healthy environment for our patients and staff.

If you are a patient and you smoke or use tobacco, ask your nurse about:

- Our handout called “Resources to Quit Smoking or Using Tobacco”
- Nicotine patches or gum to use during your stay
- Quit-smoking session with a pharmacist
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 UWMC’s Inpatient Rehab Unit, call 8.4800 from your bedside phone. From outside the hospital, call 206.598.4800.

After discharge, call your primary care provider or UWMC’s Rehabilitation Clinic: 206.598.4295
UWMC Facilities and Services

What to expect

In this section:

• Food and Drinks
• Maps and Finding Your Way
• Transportation and Parking
• Other Resources

If you need something while you and your family are here, please ask.

~ UWMC Staff

Food and Drinks

Cafeteria

The hospital cafeteria is called the Plaza Café. Take the Pacific elevators to the 1st floor and follow the signs to the Plaza Café.

Ask for the weekly menu at the front desk of the Rehab Unit. The menu is available in many non-English languages.

Espresso Stands

• Near the Gift Shop on the 3rd floor (main entry level). Weekday hours are 6:30 a.m. to 9 p.m. Weekend hours are 8:30 a.m. to 4:30 p.m.
• In the rear of the Plaza Café sitting area on the 1st floor. Open weekdays only.
• In the Surgery Pavilion on the 1st floor. Open weekdays only.

**After-Hours Food Cart**

The after-hours Food Cart stops at many places in the hospital every day between 7 p.m. and 3:30 a.m. The schedule of stops is posted on each unit. Or, ask a staff person.

**Ordering Food for Delivery While at UWMC**

You may order food from outside sources for delivery to the hospital. **Check with your nurse before ordering.** Please meet the delivery driver outside the 3rd floor main entrance to protect patient privacy.

**Maps and Finding Your Way**

You can get floor maps of the hospital at the Information Desk on the 3rd floor (main entry level). Please ask any staff person with a badge for help with directions.

**Transportation and Parking**

If you have a transportation question, talk with someone on your healthcare team. A social worker may be able to help you with your transportation needs.

**Parking**

There are 2 places where patients, families, and visitors can park when coming to UWMC: the **Triangle Garage** and the **Surgery Pavilion Garage**.

- Ask at the nurses’ station for validation for reduced parking fees for your family members and friends.
- If your visitors plan to leave and return on the same day, ask at the gatehouse for an **in/out access card**.
- People with disability or mobility parking needs may park in the Surgery Pavilion garage. Or, use valet parking at the main entrance to the medical center and on level P1 of the Surgery Pavilion.
UWMC Pharmacy

The Outpatient Pharmacy is on the 3rd floor of the hospital, near the Cascade Elevators. You must pay for your prescriptions when you pick them up. They are not included in your hospital bill. You may pay with cash, check, Visa, or MasterCard.

The pharmacy may need to see your drug benefit card. This card may be different from your medical insurance card.

Business Services

Patient and Family Resource Center

The Patient and Family Resource Center is in the 3rd floor lobby near the main entrance of the hospital. The resource center offers UWMC patients and families free use of computers, internet, printer, fax, phone, and copier.

Fax

- Visit the Patient and Family Resource Center in the lobby on the 3rd floor.
- Contact Social Work and Care Coordination.
- Ask your nurse.

Computers and Internet Access

Visit the Patient and Family Resource Center in the lobby on the 3rd floor.

Notary Services

Free notary services in the hospital help you and your family notarize documents related to your healthcare. Ask at the front desk on the floor where you are staying to contact Social Work and Care Coordination for you.

Other Resources

Cash Machines (ATMs)

- Near the cashier’s office on the 3rd floor (Bank of America).
- Near the Pacific elevators on the 1st floor (WSECU).
- Across the street at the rear of the hospital, outside the South Campus Center (U.S. Bank).

**Washers and Dryers**

There are washers and dryers that you and your family may use. Ask someone on your care team for more information.

**Gift Shop**

The Gift Shop is in the main lobby on the 3rd floor (main entry level). The Gift Shop sells newspapers, magazines, greeting cards, phone cards, stamps, gifts, candy, snacks, and drinks.

**Mail**

Mail is delivered to patient floors every day. Mail for inpatients should be addressed to:

Patient Name  
Room Number  
Box 356144  
University of Washington Medical Center  
1959 N.E. Pacific St.  
Seattle, WA 98195  

Outgoing mail may be placed in the mailbox at the nurses’ station or in the U.S. mailbox in front of the hospital, near the bus stop.

**Using a Webpage to Stay in Touch**

You can create a free, private webpage to share information about the patient with family and friends. Your webpage lets you stay in touch without having to make phone calls or send emails. To get started on your webpage in English or Spanish, visit one of these websites:

- [www.carepages.com](http://www.carepages.com)
- [www.caringbridge.org](http://www.caringbridge.org)

For help setting up your webpage, visit the Patient and Family Resource Center in the 3rd floor lobby.
Your Care Team

Helpful information

In this section:

- You: The Patient
- Medical Staff
- Nursing Staff
- Allied Health Professionals
- Support Staff
- Peer Mentors for People with Spinal Cord Injury
- Caregivers
- Advocates
- Others Who Can Support You

The staff of the rehab unit is unbelievably vital. What they really “rehabilitate” is our hearts and minds. Many thanks to the staff!

~ Patient Advisor

Note: Care team members are listed in alphabetical order in each section.

You: The Patient

We strongly urge you to:

- Ask questions about your care and treatment.
- Share information about your care concerns, needs, preferences, and treatment.
- Accept responsibility for learning how to meet your healthcare needs.
- Learn about all your medicines. Know what their names are, why you take them, what they do, and what your usual doses are.

Rehab unit staff are here to help. Be sure to ask any questions that you have.
• Do as much as you can for yourself and stay as independent as you can.

• Take an active role in your healthcare.

• Read the brochure “Information About Your Healthcare” to learn about your rights and responsibilities. This brochure also explains advance directives and durable power of attorney. You will find it in your Discharge Binder.

**Medical Staff**

Many people serve special roles as part of your care team:

**Attending Doctor**

Your attending doctor, also called a *physiatrist*, is a specialist in physical medicine and rehabilitation. Your attending doctor directs your care and watches over the care plans and training of resident doctors (see “Resident,” below).

**Medical Student**

A medical student attends medical school. As a part of their medical education, medical students work closely with the residents to learn about caring for patients in the hospital. At times, medical students receive training on the Rehab Unit.

**Resident**

A resident is a doctor who has graduated from medical school and is in training in a special medical or surgical area. An R1 (Resident 1), also called an *intern*, is a resident in the 1st year of training. An R2 is in their 2nd year, an R3 is in their 3rd year, and an R4 is in their 4th year.

**Nursing Staff**

You receive nursing care 24 hours a day, 7 days a week. Many of your nurses are certified in rehabilitation nursing.

**8-North Manager**

The 8-North manager oversees all of the nurses on your care team and is the main person responsible for all operations on the Rehab Unit.
Charge Nurse

The charge nurse creates the daily nursing assignments, may help in your care, and is in charge of keeping the many services within the Rehab Unit running smoothly.

Clinical Nurse Specialist

A clinical nurse specialist (CNS) is a nurse who has advanced clinical training with a master’s degree. A CNS is an expert in a special aspect of nursing, such as pain management or wound care. The CNS consults with other nurses and the doctors.

Nurse Practitioner

A nurse practitioner, also called an advanced registered nurse practitioner (ARNP), is a registered nurse with a graduate degree who has received special training to diagnose and treat common medical problems. Many ARNPs have advanced clinical care skills in a specialized area.

Patient Care Technician

Patient care technicians (PCTs) care for patients as directed by an RN. They help you with personal care such as bathing, dressing, feeding, and toileting. They also help you with getting out of bed and walking on the unit. A PCT may also be called a nurse’s aide, hospital assistant, or orderly.

Primary Nurse

Each patient has a primary nurse who provides bedside care and coordinates all aspects of daily care with other teams and services. All nurses at UWMC are registered nurses (RNs).

Allied Health Professionals

There are many other health providers who work with your doctors and nurses to provide the best possible care for you. These special providers include:

Dietitian

A dietitian is an expert in food and nutrition. Your dietitian will assess your nutritional needs and advise your care team about the best diet for you.
When needed, dietitians also teach patients and their families how to follow any special diets after leaving the hospital. Registered dietitians have a bachelor’s degree, and many have a master’s degree.

**Occupational Therapist**

An occupational therapist (OT) assesses how well you can do daily tasks such as dressing, bathing, and cooking, and works with you to improve your skills in these areas. These chores are also called “activities of daily living” (ADLs). An OT may also provide aids, devices, or equipment to help you do ADLs. OTs are licensed and have a degree at the master’s level or higher.

**Pharmacist**

A pharmacist gives information to medical and nursing staff about the uses, dosage, and effects of medicines. All clinical pharmacists at UWMC have a PhD or Doctor of Pharmacy degree. Pharmacists also teach patients and their families about the medicines they will use during their stay and after they leave the hospital.

**Physical Therapist**

A physical therapist (PT) assesses how well you can move around your environment. The PT can suggest exercises, therapies, and medical equipment to help you safely move more easily and become stronger. If needed, the PT and/or OT may work with you on using a wheelchair. PTs are licensed and have a degree at the master’s level or higher.

**Recreation Therapist**

A recreation therapist assesses a patient’s social functioning. They can also design activities to improve the physical, mental, emotional, and social functioning of people who are disabled after a trauma or disease. All recreation therapists have a bachelor’s degree, are nationally certified, and are registered in the state of Washington.
Rehabilitation Counselor
A rehabilitation counselor helps you with your plans to return to work, school, or other activities. Computer access allows patients to stay in touch with friends and family, and allows students to continue with their school work. Rehabilitation counselors can also provide resources and career guidance, or help you set up volunteer work. They have a master’s degree and a national certification.

Rehabilitation Psychologist/Neuropsychologist
An attending rehabilitation psychologist will see you during your hospital stay. You can also meet with your psychologist after you leave the hospital to talk about adjustments and coping with injury and the changes you are facing. Your psychologist will work closely with you, your family, and the team to address issues such as life transitions, depression, anxiety, sexuality, pain management, sleep habits, and more. Your psychologist may also provide education for you and your family on your new condition.

If you have any problems with your memory, attention, problem-solving, or other thinking skills, your psychologist may advise neuropsychological testing while you are in the hospital. Your psychologist may also advise a more complete outpatient assessment, depending on your situation. A technician called a psychometrist will give you these tests, if they are needed.

You may also see a psychology fellow, a psychologist with a PhD who is receiving specialized training in rehab psychology, or a psychology resident, who is completing PhD training. Your attending psychologist oversees both the fellow and resident.

Respiratory Therapist
A respiratory care therapist (RT) assesses how well you can breathe, and treats you if needed. Your RT will work closely with your doctor and nurse to provide the best oxygen therapy, secretion (phlegm) removal therapy, and pulmonary (lung) diagnostic monitoring while you are in the hospital.
If needed, your RT will also arrange for you to have oxygen and other equipment when you go home. An RT is licensed and has national credentials.

**Social Worker**

A social worker provides support and help with your discharge planning and options. A social worker is licensed and has a master’s degree. They can help you with:

- Care coordination after you leave the hospital
- Finding resources for caregiver support, community support, and ongoing rehabilitation in your home or in an outpatient clinic
- Finding community healthcare providers
- Referrals for continuing care

**Speech Therapist**

A speech therapist assesses how well you can learn, speak, swallow, and understand and use language (what you hear, read, say, and write). Speech therapists suggest methods or equipment to help you develop new ways to communicate, learn, or swallow. Speech therapists are licensed and have a master’s degree.

**Support Staff**

**Case Management Team**

Your case management team includes a *patient access coordinator* and an *inpatient case manager*. These members of your care team work with your insurance company to help with your admission to the rehab unit.

The inpatient case manager is the main contact with your insurance company after you are admitted to the hospital. This staff member also helps with continued authorization for your hospital stay, facilitates group team meetings, helps with documentation of care, and works closely with the social worker on discharge planning.
Environmental Services Staff
These staff members clean your room every day, as well as the lounges and restrooms on your floor of the hospital.

Financial Services Counselor
A financial services counselor can help you and your family understand your hospital bills. They also work with insurance companies, the Department of Social and Health Services (DSHS), and Medicare to make sure the hospital receives payment for services. If needed, they can help you apply for Medicaid. For directions to Financial Services, ask at the Information Desk on the 3rd floor. (See the section on “Financial Concerns,” page 23.)

Operation Supervisor
The operation supervisor works closely with the nurse manager to help the Rehab Unit run smoothly. The operation supervisor makes sure that the non-medical needs of our patients and families are met. The operation supervisor also oversees the interactions between patients and staff.

Patient Services Specialist
A patient services specialist (PSS) supports our patients and families in nonmedical ways. A PSS gathers your daily menu choices, issues stickers for parking discounts, and is available at the front desk to answer basic questions. The PSS also does office work, answers the phone, and helps the doctors, nurses, and families with other hospital services.

Peer Mentors for People with Spinal Cord Injury
The peer mentor program is for people who have had a spinal cord injury. A peer mentor is a patient who has gone through something similar to what you are going through. You may be able to meet with a peer mentor in person.

If you would like to meet with a peer mentor, please talk with your rehab psychologist.
Caregivers

Before you leave the hospital, decide who will be your primary caregiver. This may be your partner, a family member, or a long-time friend. This person may care for you short-term while you are finding a caregiver to hire.

Your caregivers’ schedules will depend on your needs. Some people need a caregiver for only a short time, need more than 1 caregiver at a time, or rotate between 2 or more caregivers.

Advocates

An advocate is someone who believes in you, the patient, and serves as your support and spokesperson. An advocate is someone who sticks up for you. A caregiver can also be your advocate, if that works well for both of you.

Your advocate:

- Is someone you choose, who is willing and able to act on your behalf.
- Is someone who can talk with and work with your healthcare team and your family.
- May be a partner, sibling, parent, child, or a trusted friend.

Your advocate may help with only 1 issue or many issues, only once or many times, for a short time or a very long time. Some advocates may need to fill out forms, such as the durable power of attorney form.

Others Who Can Support You

You may ask for help and support from a neighbor who does not otherwise help in your care or serve as an advocate. For example, your neighbor may be willing to bring in your mail and newspaper each day. Some patients have a trained service dog that helps with tasks of daily living.

There are also many services or groups in your community that can provide support. These include the MS Society, the Spinal Cord Injury Association of Washington, Alcoholics Anonymous, and Narcotics Anonymous.
Good friends helped connect me with the volunteer office at the MS Association because they knew I was going to need help with physical needs. They found a match for me.

I called Victoria and she was at my house in 20 minutes. Victoria was a dancer with the San Francisco Ballet, and now works in the costume shop of a local ballet company.

This connection changed my life. Victoria helps with my finances, answers mail, waters plants, and holds power of attorney for me. But also, through my friendship with her, I am able to go to ballets, and meet dancers, directors, and designers – things that I never would have done without this connection.

I feel like a “Make-a-Wish” child because I love ballet and trust Victoria with my life needs. You have to risk reaching out – for me, it worked out beautifully.

~ Patient Advisor

Many rehab patients find that it is life-changing when they risk reaching out for help.
Members of your care team are described in detail in the section called “Your Care Team,” starting on page 15. All team members will meet with you during the admission process to coordinate the care you will receive during your hospital stay.

Steps to Develop a Plan of Care

Your care team will work with you to create your plan of care. Main steps in this process are assessment and setting goals.

Assessment

This step involves a review of your:

- Health status
- Medical condition
- Mental health

This information, along with results from any diagnostic tests, provides a baseline that you and the rehab team can use for setting your rehabilitation goals.

Setting Goals

Your team will ask you questions about your long-term goals for rehabilitation. You and your team will use these goals to develop your plan of care.

Your discharge goals are set during your first assessment process. Your care team will discuss these at your weekly plan of care conferences.

Your Plan of Care

Your plan of care will be unique to your needs, goals, values, and situation. Sometimes your plan of care must also take be adjusted based on your finances.

Your plan of care and your therapy schedule will include at least 3 hours a day of occupational therapy (OT), physical therapy (PT), and speech therapy.

During your stay, your care team will talk about your plan of care and review your treatment during rounds and at your plan of care conferences (see next page).
Rounds

Members of your care team will visit you each day. This is called “rounds.” Rounds may happen at any time of day.

The purpose of rounds is to check on your progress toward your discharge goals. During rounds, please share how you are feeling. Talk about any concerns you have about your health or social condition and treatment.

Rounds are a good time for you, a family member, or a loved one to ask questions. It may help to write down your questions and post them in the room for the team to answer.

Plan of Care Conferences (Interdisciplinary Team Conferences)

All the members of your care team meet with you at least once a week to review your progress. These meetings are called “plan of care conferences.” They are a vital part of your rehab stay.

You and your designated family member, loved one, or advocate are welcome to attend these meetings. Plan of care conferences last about 10 minutes.

Tips on Setting Goals

• Goals should be challenging but also realistic. Set goals that you know you can reach. Unrealistic goals can be frustrating.
• Ask yourself what each of your goals will require of you.
• Do not lose sight of your goals.
• Goals need to be specific.
• Your goals may change during your stay and that is ok.
• Some people feel that writing down their goals is much more powerful than just thinking about them. You can write out your goals, or have someone record them for you.
• Some people find it helps them to stay focused on their goals if they have a “personal mission statement.” Creating your own mission statement can help you know what is important to you and may help guide your decisions. Your Interdisciplinary Report will also list your goals.
• Communication with your team is important in meeting your goals.

• Here are a few examples of goals that you may set:
  - I will be able to get to the bathroom to use the toilet and shower with a little help.
  - I will be able to get dressed by myself.
  - I will be able to safely walk around my house with a walker.
  - I will be able to direct people in how to help me get to my wheelchair.
  - I will know all my medicines and when to take them.

**Being a Partner in Planning Your Care**

Here are some tips from patients, family members, and UWMC staff about how to best partner in your care planning:

• **Attend plan of care conferences** so you are clear about your progress, goals, and needs. These meetings are a great place to bring up issues that are important to you. You and your family or loved ones can work with your care team to develop your care and discharge plans.

• **If you have a major issue** or one that may take more time than a plan of care conference allows, ask to have a separate meeting.

• **Ask questions.** This is VERY important.

• **Use the resources available** and ask about more resources if you cannot find what you are looking for. An example would be support groups in your area.

• **Prepare ahead** for plan of care conference. Write down your list of questions and issues, or ask someone to do this for you.
Change as a Part of Life

Your rehab psychologist and social worker are here to help you accept change as a part of life.

Change can be slow or fast. This is true when the change is major, such as severe injury, or more mild, such as when we start a new job.

Change as a Factor in Rehabilitation

Rehabilitation recognizes that change is a part of living. Supporting your ability to adapt to change can make things go better. Your care team plays a part in this process.

We want to work with you, your family, and your loved ones to find ways to cope with and manage the effects of change. This is why we ask you what you did to successfully adapt to past changes, and what your support network of family and friends is like.

Readiness for Change

How you deal with change depends on your personality, how easily you move from one idea to another, how you think of yourself, your culture and upbringing, and more.

Each person in rehab has their own changes to deal with, and different ways to manage those changes. Your readiness to redefine yourself will be unique, and we will respect your process.

Your emotional reserves and physical energy play big parts in how ready you feel to face each day. Your feelings are your starting point, so be sure to recognize and validate them.

How supported you feel will also affect your readiness for change. Talk with your care team about your feelings. This will help us work together to reach your goals.

Adapting to Change Over Time

We may not like change, but we can get better at adapting to it. Over time, you may grow more at ease with the changes. Learning how and where to find support can help.
The change process involves loss and letting go of the old, while also embracing the new. As we come to terms with loss, we go through the stages of grief. These stages include feelings of disbelief, anger, sadness, bargaining, and acceptance – and not always in that order. Having some or all of these feelings is normal. They are a part of how we cope with change.

Support from others can help you handle the grief you feel. This support can come from those who have been through something similar, or from friends or counselors who are willing to help.

With time, you will learn what some of your options and opportunities are. Some of these may surprise you.

**Planned Change**

Your care team will work with you to help you plan changes. These changes will be based on what you prefer and what they know about your condition. Planned change is based on the timing of your specific goals. Some people do best with planned change, especially if they like to use logic and practical solutions.

Planned change is a step-by-step process. It usually involves schedules, appointments, and gathering information. If this is how you like to work, consider seeking information from your care team, the internet, UWMC’s Patient and Family Resource Center, members of a support group of patients and families, and other sources.

**Unexpected Change**

If you allow yourself to be open to them, some opportunities may seem to drop into your lap. This can occur when others bring information to you didn’t expect, or when outside forces show you something that you didn’t know before.

Sometimes, meditation or prayer can open possibilities. At other times, one contact can start you on the trail of new resources and helpers. Insight from therapy or counseling can reveal new ways to look at a problem.
Unexpected change may occur when time has passed and your reaction to your loss has shifted. Changes in funding or in care coverage can also open new doorways.

Whatever the source, unexpected change may take place for you. The choice of how to work it into your life will be yours.

“I don’t like my situation, but I can choose to do the best I can in my situation.”

~ Patient Advisor

Notes
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 UWMC’s Inpatient Rehab Unit, call 8.4800 from your bedside phone. From outside the hospital, call 206.598.4800.

After discharge, call your primary care provider or UWMC’s Rehabilitation Clinic: 206.598.4295
Support

Being an advocate for yourself and others

In this section:

• First Steps: What Advocates Need to Know Right Now
• Next Steps: What Advocates Need to Know Long-term
• Being an Advocate for Yourself and Others
• Roles for Advocates
• Legal and Other Appointed Advocates
• Long-term Care Advocate
• Caregivers
• Others in Support Roles

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
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.
Financial Concerns

Helpful information

In this section:

- Planning Ahead
- UWMC Financial Counseling
- Check Your Health Insurance Plan
- Public Health Insurance Plans
- Disability Income Insurance
- Other Options

Knowing your needs helps you make plans about paying for them. It really helps to start thinking about these issues as soon after admission as you can.

~ Patient Advisor

Planning Ahead

Planning your finances, both your income and insurance, is a key part of being prepared for rehab and beyond. Most likely, you will need to make both short-term and long-term decisions.

Your case manager will give you a benefit profile that reviews your insurance coverage. If you are not from Washington state, your social worker may contact someone who knows about programs in your state to advise you and answer your questions. UWMC Financial Counseling staff can also help.
Short-term Issues
- Paying for rehabilitation
- Transportation and living expenses for your caregiver(s)

Long-term Issues
- Paying for ongoing care, including a caregiver, if needed
- Source of income
- Paying for medicines and medical supplies, if needed

UWMC Financial Counseling
UWMC financial counselors can help you and your family:
- Understand your hospital bills and paying for your hospital stay
- Work with insurance companies, public insurance plans, and the Department of Social and Health Human Services (DSHS)
- Apply for Medicaid (called “Apple Health” in Washington state) and other financial aid

For help with applying for insurance after you leave the hospital, call UWMC - Roosevelt Clinic at 206.598.4388 to set up a time to talk with a financial counselor.

Check Your Health Insurance Plan
Most insurance plans pay for rehabilitation. There are many different insurance policies. They have different levels of coverage and limitations. Some do a good job of covering your costs, but others may leave you with big gaps in coverage. Check your plan carefully to find out if it covers:

- Inpatient hospital stay. Does your policy cover inpatient charges at a certain percent (such as 80% or 90%)? Or, do you pay a set co-pay per day while in the hospital (such as $100 per day up to a certain maximum, such as $300)? If your policy pays a percent of the costs, this means you will have a larger bill to pay yourself.
• **Waiting periods.** Some insurance plans require that you be a member of their insurance plan for a certain length of time before you are eligible for some benefits.

• **Coordination of benefits.** If you are covered by more than one insurance plan, such as through your employer as well as your spouse’s employer, you will need to check with the secondary policy to find out its rules on coordination of benefits. This will help you know what expenses your secondary policy will cover after your primary coverage pays.

**Insurance Coverage for Medicines**

Here are some questions to ask the inpatient rehab pharmacist about your health insurance plan’s prescription drug coverage:

• **Does your insurance cover prescriptions at a certain percentage (such as 50%, 80%, or 90%)?** Or, do you pay a set dollar amount co-pay for each prescription (such as $10 for each prescription per month)?

• **Does your insurance provide different coverage based on whether the drug is a “generic” or a “name” brand, or what “tier” it is in?**

• **Does your insurance offer a mail-order pharmacy for medicines?** These mail-order pharmacies often allow you to get a 3-month supply of medicines for a lower co-pay than if you went to a local pharmacy.

Some drug makers offer financial aid for people who cannot afford to buy the medicines they have been prescribed. Ask your social worker for more information.

These resources may also be helpful:

• **GoodRx:** [www.goodrx.com](http://www.goodrx.com). This website allows you to compare prices and find coupons for prescriptions.

• **RxAssist:** [www.rxassist.org](http://www.rxassist.org). This website is sponsored by Volunteers in Health Care. You can search the database for application forms.
- **Medicare**: [www.medicare.gov](http://www.medicare.gov) or call 800.633.4227 (toll free).

- **NeedyMeds**: [www.needymeds.org](http://www.needymeds.org). This website includes program information, forms, and other helpful links.

- **Partnership for Prescription Assistance**: [www.pparx.org](http://www.pparx.org) or call 877.923.6779 (toll free). This program is for Washington state residents.

### Public Health Insurance Plans

#### Medicare

Medicare is a health insurance plan provided by the U.S. government. It is for people who are on dialysis, have had a kidney transplant, have been on Social Security Disability for at least 2 years, or are at least 65 years old. Medicare has a number of deductibles and co-pays.

There are 3 parts to Medicare:

- **Part A** covers hospital stays.
- **Part B** covers doctor fees for inpatient and outpatient services, as well as all approved outpatient expenses.
- **Part D** covers prescription drugs.

#### Medicare Supplements or “Medigap” Policies

These policies supplement your Medicare coverage. Most times, they pay the Medicare co-pays and deductibles, but nothing extra. Having Medicare and a “Medigap” supplement will likely cover most of your costs.

#### Medicaid (Washington Apple Health)

Medicaid in Washington state is known as Washington Apple Health. This is a health insurance plan through the State of Washington for people who have a very low income and are medically disabled. It will pay 100% of covered medical costs. Talk with your financial counselor or social worker to see if you qualify.
**Washington Healthplanfinder**

Washington Healthplanfinder ([www.wahealthplanfinder.org](http://www.wahealthplanfinder.org)) is an online marketplace for health insurance. It is run by Washington Health Benefit Exchange. It provides:

- Side-by-side comparisons of health insurance plans
- Financial help to pay for copays or monthly premiums
- Expert customer support online, by phone, or in person

**Disability Income Insurance**

If you were working before coming to the Rehab Unit, your employer might provide disability income insurance. There are 2 types of this kind of insurance: short-term and long-term.

- **Short-term disability insurance** pays part of the salary you were earning while you are off work for a medical reason. This is often around 60% of your usual salary. Short-term disability usually covers your salary for 3 to 6 months.

- **Long-term disability insurance** pays a part of the salary you were earning, often 60%, for as long as you are considered disabled and unable to work. But, you usually need to be disabled for a minimum length of time, such as 90 days, before benefits will begin.

**Social Security Disability (SSD)**

The Social Security Administration (SSA) has its own definition of “disability” for various illnesses, such as kidney disease or diabetes. It can take many months to be approved for disability benefits after you apply.

If you are approved, the amount you receive each month is based on how much money you have paid to Social Security through payroll taxes. SSA must consider you disabled for at least 5 months before benefits can begin. Also, your disabling condition must be expected to last at least 1 year to be eligible for SSD.
Supplemental Security Income (SSI)
SSI is a disability income program offered through the SSA for disabled people who have not worked enough to pay much to Social Security and are not eligible for SSD. The disability rules are the same as for SSD. But, SSI has strict income and financial limits.

Other Options
If you are not eligible for any of the above resources, here are some other options:

- Put aside money to help pay the bills.
- Borrow money from family and/or friends.
- Try fundraising. Some people have success with friends and members of their communities holding fundraisers to help pay medical costs. You can ask your social worker for more details.

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 the Inpatient Rehab Unit, call: 206.598.4800

After discharge, call your primary care provider or UWMC’s Rehabilitation Clinic: 206.598.4295
Care After Discharge

Helpful tips

In this section:
- Preparing for Discharge
- From Rehab Staff
- Tips from Patient Advisors
- Caregivers
- Before Hiring a Caregiver
- Working with Your Caregiver

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

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 quality-of-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.
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

- 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
Managing Caregivers

Helpful tips

In this section:

- Personal Boundaries and Caregivers
- Caring for Your Caregivers
- Thoughts About Caregivers

Hiring caregivers is hard, necessary, and a hassle, but it is doable. We have had good success. I suspect it is easier when you have another person to share the burden with, and I suspect that the process of hiring has been easier for us because my husband is married to a rehab nurse! I’m confident he’s a better manager than I am, and the length of time people have been with us is probably due to his personality and the way he manages caregivers.

~ Family Advisor

Personal Boundaries and Caregivers

Good boundaries define limits and mark dividing lines. The purpose of a boundary is to keep “turfs” and territories separate. Personal boundaries can mean:

- The psychological, physical, and emotional space between you and someone else
- Morals and values
- Respect for yourself and others

Staying as independent as you can helps you set good personal boundaries.
What do personal boundaries have to do with my care?

Personal boundaries set the “tone” for the relationship between you and your caregivers. Caregiving relationships are complex because you need help, and you may need very personal care. It can be hard to have family members or loved ones in that role. You can feel vulnerable, even while you are grateful for their support.

Boundary problems that may occur when a family member is also the caregiver are:

- The caregiver takes over all decision-making, doing what they feel is “best.”
- The person receiving care expects the family caregiver to be on-call 24 hours a day, 7 days a week.

Some examples of boundary problems with hired caregivers are:

- The caregiver asks to borrow $10 and doesn’t pay it back when promised.
- The person receiving care asks the caregiver to do tasks that are not required or part of their job description.

What does it mean to have good boundaries?

Good boundaries are maintained when you stay as independent as you can. This means directing your own care and making your own choices.

Some issues to watch for are:

- Worrying about being a burden
- Wanting to keep the caregiver “happy”
- Letting someone else make choices
- Not wanting to make your wishes known

Good boundaries help you:

- Take charge of things you can control
- Ease the burden of decision-making
- Have things done your way
What can I do to keep good boundaries?

Be assertive in your interactions with others. This doesn’t mean you always get what you want, but it does mean that you get to express your needs and wants.

Here are examples of what it means to be aggressive, passive, passive-aggressive, and assertive:

- **Aggressive**: My way, or not at all.
- **Passive**: Your way, or not at all.
- **Passive-aggressive**: My way only, but you can think it’s your way.
- **Assertive**: Let’s negotiate: I want X and you want Y, so let’s talk.

How do I keep strong boundaries with “unpaid” caregivers?

Think about how you normally are independent and assertive with your family and friends. Most likely, you talk about:

- What you need
- What they need
- How you want things done
- How they want things done

It can be harder to keep good boundaries when your caregiver is also your spouse, parent, or friend. Talk with your loved one about how adding caregiving may change your relationship. Talk over how to manage the relationship so you can maintain your role as spouse, parent, and child/parent. Talk about issues until you come to a solution you both can live with.

How do I keep strong boundaries with paid caregivers?

When you hire a caregiver, you are setting up a home-based business. Think about what you’d expect from yourself as a “good employee.”

Make sure your expectations are clear from the beginning of your relationship with a caregiver. This means agreeing on:
• Start and end times  
• Job tasks  
• Pay scale and pay dates  
• How you will handle requests about time off and pay raises  

**What do I do if boundaries get blurred and complicated?**  
Boundaries are challenged many times in any relationship, and especially in a relationship with a caregiver. Remember that you can always back up and start over. If you need help, you can ask peers, find resource guides, or get counseling.  

**Caring for Your Caregivers**  

**Counseling Services for Caregivers**  
In the Seattle area, an **unpaid caregiver** has access to counselors through Evergreen Hospital in Kirkland, WA. The program is funded by grants from United Way of King County and Seattle-King County Aging and Disability Services.  

The purpose of the counseling program is to help caregivers take better care of themselves. This also helps them provide better care. Counseling sessions focus on problem-solving, self-care, managing stress, and helping the caregiver find the community resources and education programs.  

Volunteer caregivers can call 206.923.6300 or 800.548.0558 for more information about this free counseling program.  

**Thoughts About Caregivers**  
These tips on dealing with hired caregivers come from a registered nurse whose husband has quadriplegia:  

**When Hiring a Paid Caregiver**  
• **Be flexible.** If you can, let go of any biases about gender, sexual preference, race, etc. We have had a wide range of people work for us – male and female, gay and straight, white, black, and Indian. The wider you leave the door open, the more options there are. The bottom line for us is getting someone we trust who can do the job. Our focus is on
whether they are a good, trustworthy person who can learn how to do the needed tasks.

- **Safety checks.** Do all the advised safety checks before hiring a caregiver: personal and business references, and a Washington State Patrol check. If you have a bad feeling about someone, trust that feeling. Keep looking until you find the right caregiver for you.

- **Experience.** Almost anyone can learn basic caregiving tasks, so don’t worry too much about the past caregiving experience of someone you are thinking about hiring. Sometimes it is good to start with a clean slate. Most people can learn to catheterize, do a bowel program, do transfers, and other tasks. Focus on the person’s qualities and integrity. Know that you can teach them the specific tasks you need done.

- **Advertising.** There are many good ways to advertise for a caregiver. When placing an ad, give a short list of your requirements (such as DSHS “qualified preferred” or “experience preferred”). Here are some ideas for where to advertise:

  - **Online.** Craigslist.com is an easy way to advertise online. There are other online resources for finding caregivers such as www.caring.com.

  - **Flyers.** Posting for caregivers in local college newspapers or placing flyers at local schools or church bulletins can also be a good way to find caregivers.

  - **Agencies** can help you with hiring caregivers.

  - **Word of mouth.** Your friends and your caregivers can help you find other caregivers.

- **Get help with the interview process.** Ask someone who knows you, cares about you, and is able to “read” people well to help you interview potential caregivers. Two heads are better than one.
• **Help yourself handle the stress.** Hiring a caregiver is hard and stressful, but it is doable. Try to make the process as effective and efficient as possible.

• **Don’t feel you have to do it all yourself.** If hiring is very hard for you and you cannot find the right caregiver for your needs, you can choose to have someone else do the hiring. A temporary employment agency can be a great resource, but they will charge a finder’s fee. One family hired a part-time speech pathologist to do the hiring, interviewing, and narrowing down the list to a couple of final candidates.

• **Get short-term help if needed.** It can be hard to find a long-term employee, so remember that there are resources when you need help right away. One family got a short-term caregiver through Family Resources. This worked out well until they were able to hire a long-term caregiver. There are many home healthcare agencies that may be able to help you find short-term caregiving.

• **Network, network, network.** Whenever you can, connect with others who might be able to help you in the future – with hiring, with coverage when a caregiver needs a break or is on vacation, or with other tasks that need doing. Try to line up relief workers before you need them, by getting phone numbers and checking their rates ahead of time. When a crisis occurs, it is good to be prepared.

**Working with Your Employee**

• **Treat employees with respect.** Being polite, saying “please” and “thank you,” helps create good working relationships. At the same time, make sure it is clear who is in charge. You are the boss and have the final word. Be friendly, but keep your boundaries in place, so that it is clear that you are the boss and decision maker.

• **Give your caregiver time off.** Work out other resources so that you can your caregiver time off. Everyone needs a vacation to get refreshed.
• **Quality control.** From time to time, check to make sure the job you expect to have done is being done, and done the way you want. Even the best caregiver can slip into poor habits over time.

• **Be ready for the unexpected.** What if a caregiver walks out, or doesn’t show up? Or what happens if you want to fire your employee? It is important to plan ahead for these types of issues. You may ask a friend or family member if they are willing to come help you on an emergency-only basis. Or, you might have an agency you could call. Start figuring out now how to find a replacement in emergencies.

See “Care After Discharge,” starting on page 49, for more information and thoughts about working with caregivers.

**Notes**
**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
Self-care
It’s up to you

In this section:
• Good Habits
• Planning Your Day
• Managing Fatigue
• Getting Help
• Supplies
• Staying Current

I learned that you have to ask for what you want. You are in a new role, one you haven’t been in before. Speak up and ask for good care. Make sure you take good care of you.

~ Patient Advisor

Good Habits

• It is important to take good care of yourself. Attend to all aspects of your well-being – your physical, spiritual, and emotional health.

• The basics stay the same: eat right, exercise, and get plenty of rest. Avoid smoking. If you drink, do so in moderation.

It is important to do as much as you can do for yourself and to stay active.
• Staying hydrated is important, but it can be easy to forget. Try setting a goal of drinking enough water and make use of electrolyte replacement drinks.

• Keep up as many of your old friendships as you can. You are still you, even sick or injured.

• Do as much as you can do for yourself and stay active.

• Learn good communication skills, or improve the ones you already have. These skills will help you take good care of yourself.

• Assess whether you will need any new healthcare providers. Get regular check-ups.

• If there are personal tasks you used to do that you are no longer able to do, such as trimming your nails or shaving, arrange to have them done.

• Be proactive. Knowing what you’re dealing with helps avoid accidents and embarrassment.

• You have been through a lot and could be overwhelmed by your world after discharge. Setting a schedule can help with feelings of being overwhelmed.

Planning Your Day

• You may need to learn a new level of patience. Expect that many things will take longer to do than before. You have been and will continue going through a major life event. Give yourself some grace.

• Consider using a schedule. A daily planner can help you organize your day and make it to doctor’s visits, therapies, and other treatments. Not having a schedule can lead to sleep problems, missed medicines, or nutritional issues. These can affect your recovery and overall quality of life.

• Use technology to help you stay organized. You can set audible timers on your phone or computer to remind you about when to take your medicines and other important tasks.
• Ask your caregiver to come at specific and regular times. This will help you plan your day.

• Learn how to prepare people to spend time with you. Share information about your lifestyle and schedule so they can work with you.

• Be flexible. You may wake up with a “to do” list in your head, or even written down. Keep yourself open to changing your priorities. For example, if you have 2 tasks to do, you may need to ask yourself if you have enough energy to do both, or if you should choose to do just one.

• Know yourself. Are you a morning person or a night person? Do you have more energy and are you more alert in the morning or later in the day? Plan your day to match your energy levels.

• Be realistic. How long does it take you to get ready to go out? Do you need a caregiver to help you get ready? Observe how much time it really takes you to get ready to go out, and schedule your appointments and outings based on that.

• If you’re doing something for the first time since your discharge, ask for support from a friend or caregiver. It may be frustrating, but it’s better to be cautious than to find yourself in a challenging situation.

• It may be hard to be spontaneous in planning outings with friends. Make a point to plan some activities in advance, and arrange transportation to those events if needed.

**Managing Fatigue**

• Use a mediset (a plastic box used to hold up to a week’s worth of pills) for your medicines. You might even consider buying 2 and filling them with medicines for 2 weeks at a time. This can be a real timesaver. If you do not live with young children or have them over to your home, you may also want to try “easy-open” caps for your medicines.

• Try online grocery shopping to save your energy. Many stores offer free delivery if you spend a certain amount.
• Use online shopping and catalog shopping for buying gifts.

• Try taking a shower or being bathed right before bed, especially if it wears you out. If you must bathe early in the day, plan to take a short rest right afterward.

• You can pay bills and do your personal bookkeeping online:
  - Many banks now have online bill pay, where you can set up automatic payments for your monthly bills.
  - A software program such as “Quicken” is easy to learn. It can also create a tax summary report, which you can use for deducting allowed medical expenses.

Getting Help

• If you need extra emotional support, ask for help from people you trust. If it is hard to talk with your friends or family about certain situations, so ask your therapists and doctors if they know of any resources or support groups that you can access virtually or in person.

• Take time out to recognize all of the changes that have happened. You may need to grieve some losses. Know that you are not alone. Rely on your support system. Give yourself time to adjust to the changes.

• If you need help handling the emotions that come up, ask your doctor about referrals for counseling. It may be very helpful to talk with a rehab psychologist or other mental health provider who works with people who have health changes.

• There are resources and assistance in your community, county, and at the state and federal levels. But, sometimes the application processes can be frustrating and overwhelming. Speak to your social worker or PCP. Ask them to refer you to the proper resources, including vocational therapy.
Supplies

- Plan ahead before you shop. Create a list of supplies so you get what you need. Try to arrange your list by where the products are in the store. If you can avoid running all over the store, you may get less tired. Remember that the first choice you find might not be the best item or the best price.

- Use resources such as online ordering and delivery. Many offer free delivery if you’re above a price point, or if it’s your first time shopping with their services. This can help you save your energy for things you really want to do.

- Ask your pharmacy if they can provide multi-dose medicine packets. There are several pharmacies that provide this helpful service that can make it easier to fill medisets and help prevent missing a medicine dose.

Staying Current

- Follow research related to your injury or illness. Join online or in-person support groups to learn first-person approaches, medical advancements, or clinical studies that may affect or benefit you.

- Stay current with technology, especially in ways it may help you. Ask others who are going through the same situations you are if they’ve discovered modifications that can make your life easier. Some examples of technology and how it can be used in your everyday life are listed in the “Helpful Resources” section.

- Find good resources. Connect with other people, and find out what they know and what resources they suggest. To help get you started, please see the “Helpful Resources” section.
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 at 206.598.4295.
Eating to Heal

Your nutritional needs

In this section:
- A Balanced, Healthy Diet
- If Your Appetite Is Low
- Plan Ahead
- Foods for Specific Health Issues
- Food Safety

What you eat is important for your overall health, but especially for wound healing and for your bowel program.

~ Rehab Staff Member

Good nutrition is very important after an illness or injury. The foods you eat affect your weight and how well you heal.

A Balanced, Healthy Diet

No one food contains all the nutrients your body needs. A balanced, healthy diet includes a variety of foods from each of the different food groups every day. This diet will help make sure that all your nutrient needs are met.

Eating healthy foods like fresh fruits and vegetables, whole grains, low-fat dairy products, and lean protein foods will give your body the nutrients it needs. And, since these foods are usually lower in calories, they will also help you maintain a healthy weight.

A healthy, balanced diet includes plenty of fresh fruits and vegetables.
Breads, Cereals, Rice, and Pasta
When you buy breads, cereals, and other grain products, choose whole grains when you can. Whole grains have more nutrients than grains that have been processed. For instance, oatmeal and oat bran contain soluble fiber, which reduce how much cholesterol your body absorbs.

Fresh Fruits and Vegetables
Eat a variety of fresh fruits and vegetables, especially dark green, red, and orange vegetables. The more colorful fruits and vegetables contain higher amounts of phytochemicals, which help your body fight disease.

Protein Foods
Eat a variety of protein foods. Protein foods include:
• Lean meat, poultry, and seafood
• Eggs
• Legumes (beans, lentils, peas, and soy)
• Nuts and seeds (unsalted)
• Low-fat dairy products

Fats
• Use liquid fat such as olive and canola oil. Use less solid fat such as butter, stick margarine, and shortening.
• Choose low-fat or nonfat dairy products.
• Read the “Nutrition Facts” label before you buy packaged foods. Limit foods with hydrogenated or partially hydrogenated oils (trans fats). These fats increase your risk for heart disease, stroke, and other health problems.

If Your Appetite Is Low
Here are some tips to increase calories and protein if you are having trouble eating regular meals:
• Try to eat smaller meals more often.
• Try not to skip meals.
• Add avocados or guacamole, olives, nuts, or seeds to salads and entrees.

• Add sugar, honey, jam, or syrup for extra calories.

• Add low-fat milk to soups instead of water.

• Add diced or ground meat to soups and casseroles.

• Add protein powder or nonfat milk powder to drinks, soups, mashed potatoes, pudding, casseroles, and hot cereals.

• Snack on nuts, trail mix, yogurt, or cottage cheese with fruit.

**Plan Ahead**

There may be days when you feel unwell or do not have the energy to cook. To plan ahead for these times:

• Write down your planned menus for several days. When you shop, make sure you buy everything you need for each of those meals.

• When preparing meals, make a double batch and freeze servings for later. When needed, you can thaw and reheat small portions of meat, vegetables, or casseroles.

• Keep foods on hand that are easy to prepare, such as:
  - Frozen, pre-made meals. Choose brands like Healthy Choice that contain less salt and fat. Always choose meals with less than 500 mg of sodium.
  - Nutritional shakes and drinks such as Ensure, Boost, or Carnation Instant Breakfast. Many chain stores also have their own brands that cost less than these name brands.
  - Low-fat cheese, such as low-fat cottage cheese, string cheese, “lite” cream cheese, or low-fat yogurt.
  - Dried fruit, nuts, and nut butters.
  - Single servings of pudding, custard, ice cream, yogurt, soup, fruit, or dessert.
  - Sandwiches such as grilled cheese, peanut butter and jelly, or egg or tuna salad.
- Canned foods such as tuna, baked beans, ravioli, pasta, vegetables, fruits, and corned beef hash.
- Canned or frozen fruit and vegetables.
- Instant hot cereal made with low-fat milk.
- Canned salmon, tuna, or sardines. These fish are high in omega-3 fats, which are good for your heart.
- Low-fat pasta, such as low-fat lasagna or ravioli.

**Foods for Specific Health Issues**

The foods you eat affect all aspects of your health. This includes your skin, bowel, bladder, and bone health. If you have questions about how nutrition can impact your illness or injury, work with a dietitian. Together, you can create a diet plan that fits your needs.

Here are some health issues to think about and how your food choices can help:

**Wound Healing**

Wounds need protein to heal. If you have a pressure sore or an open wound, it is very important that you eat enough protein. Ask your doctor or dietitian how much protein you should eat every day.

**Constipation**

Reduced activity, illness, injury, or surgery can cause problems with *constipation* (slow bowels). If you are constipated:

- Try eating more high-fiber foods. A high-fiber diet may also help reduce your risk of heart disease and diabetes.
- Be sure to drink enough fluids, especially if you are on a high-fiber diet. Try to drink 8 cups (8 ounces each) of caffeine-free beverages, for a total of 64 ounces a day.

If you are just starting to eat more fiber, begin slowly. Over time, increase the amount of fiber you are eating. The ideal amount is 20 to 35 grams of fiber every day, from a variety of food sources.
Some high-fiber foods include:

- Berries, fresh fruits with skin, and vegetables
- Oatmeal and oat bran, bran cereals
- Dried beans (cooked), peas, lentils, nuts
- Whole-grain pasta, brown rice

You can also make this high-fiber supplement to help add fiber to your diet:

**Homemade High-Fiber Supplement**

- 1 cup unprocessed bran
- 1 cup applesauce
- ¼ cup prune juice
- Cinnamon to taste

Combine all ingredients. Chill in the refrigerator overnight. Take 1 to 2 tablespoons, 1 to 2 times a day, with 8 ounces of water.

**Reflux**

If you have a problem called reflux, you may have heartburn, chest pain, problems swallowing, or feeling like there’s a lump in your throat. Try these tips to help reduce your symptoms:

- Eat low-fat foods.
- Instead of eating 3 large meals a day, eat smaller amounts more often.
- Avoid foods that irritate the digestive system, such as coffee, chocolate, mint, carbonated drinks, citrus, and tomato.
- Sit upright while you are eating.
- Raise the head of your bed.
- Do not eat for 3 hours before going to bed.
- Do not wear clothes that fit tightly around your belly.
- If you smoke, quit.
Food Safety

While you are healing, it is also very important to keep your food safe to eat. The 4 simple steps to food safety are:

1. **Clean.** Wash hands and surfaces often, and wash fresh fruits and vegetables well before eating.

2. **Separate.** Use separate cutting boards, plates, and storage areas for produce (fruits and vegetables) and for animal proteins (meat, poultry, seafood, and eggs).

3. **Cook.** Cook at the right temperature and keep food hot after cooking.

4. **Chill.** Refrigerate perishable foods within 2 hours. Never thaw or marinate foods on the counter. Know when to throw foods away.

Learn more about these and other food safety issues at [www.FoodSafety.gov](http://www.FoodSafety.gov).

---

**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 the Inpatient Rehab Unit, call: 206.598.4800

After discharge, call your primary care provider or UWMC’s Rehabilitation Clinic: 206.598.4295
Helpful tips

In this section:
• Home Safety
• Fire Safety
• Personal Safety
• In Case of Emergency

When I came home from the hospital, there were a million and one changes that needed to be made. I thought a lot about emergencies – making sure I could get to the phone, that I had a home escape plan with a clear path to get out, and that my windows and doors were secure. My brother-in-law installed a ramp, put in some lights around the house, trimmed the bushes, and installed a peephole that I could see out of.

~ Patient Advisor

Home Safety

Making your home safe and secure means:
• Making your home accessible for entry and exit in case of emergency.
• Knowing what to do in different types of emergencies
• Keeping yourself and your valuables safe

For your safety, apply for a handicapped-parking permit.
It will help to take a look at home and personal safety issues from a new perspective. Ask your friends, family, caregivers, and advocate(s) to help you do a full review of your home and make suggestions and changes as needed.

**Tips**

- Check your home for safety hazards. Some things may have been a problem for a while, or they may only be a problem now that your health status has changed. And, there may be new risks if you are now using a wheelchair.

- Practice your emergency plan to make sure you can access and reach handles, doorknobs, keys, fire extinguishers, etc. If you are working with a home health therapist, you can talk with them about practicing these skills in your home.

- Throw rugs are very slippery and can increase your risk for falling. For your safety, remove them from your home.

- Pets can be a safety concern. Review any new problems that need to be addressed.

- Depending on your situation, your home may need to be remodeled and have safety features added. For ideas, watch the video “Home Modification after Spinal Cord Injury” at http://sci.washington.edu/info/forums/reports/home_mod_07.asp. This video is also useful for people with other disabling conditions.

- Do some research on how to work with remodeling contractors. This is an area of business that receives a large number of consumer complaints. If you have a trusted friend who knows about construction, you may want to ask them to manage your remodeling projects.

- Always have your cell phone or other communication device nearby in case of emergencies.

- At least 1 phone in your home should work even if the power goes out.
• Keep your important phone numbers handy. If you can, program them into your phone.

• If you have caller identification (caller ID), always check it before you answer your phone.

• Install a peephole in your door at a level you can use. If someone knocks at your door, look through the peephole to see who it is before you open the door, and before you say anything to them. You may decide you don’t want to let the visitor know you’re home. It’s up to you.

• If someone you are not expecting comes to the door, you do not have to let that person in, not even a police officer in uniform. It’s OK to call a company or the police department to make sure they have sent someone to your home.

• If you have caregivers, make sure they know and follow your safety guidelines.

• Keep your valuables locked away, with a trusted person, or in a safe deposit box.

• Keep your car in good running condition, and always keep your gas tank at least half full.

• Apply for a handicapped-parking permit. These spaces tend to be in well-lit areas close to the entrance of your home, work, or other places you may go.

• Keep your medicines list with you at all times. You can keep an electronic record on your cell phone.

**Fire Safety**

• Call your local fire department and:
  - Tell them your name, address, and special needs.
  - Ask them to help you do a home fire safety inspection and develop a fire escape plan. Once your plan is worked out, be sure to practice making an escape.

• Change the batteries in your smoke alarms and carbon monoxide detectors every 6 months.
• Put fire extinguishers where you need them and where you can reach them. Make sure you know how to use them.

• To learn more about fire safety for people with disabilities, visit the U.S. Fire Administration website: www.usfa.fema.gov/prevention/outreach/media/social_toolkits/toolkit_disabilities.html.

Personal Safety

• Call your local police department and tell them about your living situation. This is especially important if you live alone, even if you have an attendant. Information they will keep on file includes:
  - Phone numbers for a relative, friend, or neighbor to call in case of an emergency.
  - Information about your medical condition and abilities.
  - Contact information for the person who has a spare key to your home.

• Ask your local fire or police department if they do home safety inspections. They can advise you on safety tips. There are also private security companies that can provide this service for a fee.

• Your neighbors can be a great help in many situations. For example, they can stay aware of your routines and keep a list of your emergency contacts to call if they become concerned. Also, a trusted neighbor can keep a spare set of keys for you.

• If you have a caregiver, be sure they have a list of your critical personal information, medical information, and emergency contacts. Your caregiver needs to know where to find:
  - Fire extinguishers and smoke alarms
  - First aid supplies
  - Water shut-off valve
  - Gas shut-off valve
  - Electrical breaker box
- Your emergency exit plan
- Your medicines and dosing schedule

- Your caregiver should follow your safety rules and keep your information private, especially if you live alone.

- If you are having problems with your caregiver, or are concerned about your safety in other ways, create a code word you can use to let a trusted person know when you need help. For example, if your code word is PEACHY, you could call the trusted friend and say, “I feel PEACHY today!” This signals your friend to help in whatever ways you have agreed upon.

- Consider taking a personal safety course.

**In Case of Emergency**

- Know what disasters could affect your area.

- Make a plan and develop an emergency kit that contains everything you would need for 3 days.

- Federal Emergency Management Agency (FEMA) provides information for emergencies for individuals with functional or access needs, including tips on making a plan and building an emergency kit. Visit [www.ready.gov/disability](http://www.ready.gov/disability) to learn more.
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 UWMC’s inpatient rehab unit, call 8.4800 from your bedside phone. From outside the hospital, call 206.598.4800.

After discharge, call your primary care provider or UWMC’s Rehabilitation Clinic: 206.598.4295

Notes

_____________________________________________________________________________________________

_____________________________________________________________________________________________

_____________________________________________________________________________________________

_____________________________________________________________________________________________

_____________________________________________________________________________________________

_____________________________________________________________________________________________

_____________________________________________________________________________________________

_____________________________________________________________________________________________

_____________________________________________________________________________________________

_____________________________________________________________________________________________

_____________________________________________________________________________________________
Follow-up Care
After you leave the hospital

In this section:
• What to Expect After Discharge
• Your Outpatient Care Team
• Coordinating Your Care
• Requesting Your Medical Records
• Medicines (First Prescriptions and Refills)
• Preventive Care: Staying Healthy Going Forward
• Solving Problems After Discharge

Preparing a patient and their family for a safe and stress-free discharge is one of the most important things we address in therapy. Our priority is to help patients and families be aware of what questions may come up once they get home, and to make sure they know who to call when something occurs.

~ Rehab Staff Member

What to Expect After Discharge

Follow-up visits with your Outpatient Care Team.
After discharge, your Outpatient Care Team will take over your care. Your attending doctor will arrange for your follow-up visits with this team. It is important to attend these appointments to help manage your ongoing medical and rehab issues.
Medicines: first prescriptions and refills. You will receive prescriptions for your medicines before discharge. You will also need to get refills as your medicines get low.

Preventive healthcare. Your Outpatient Care Team will partner with you to create a long-term plan for your health.

Problem solving. There are resources to help with issues that may arise after you leave the hospital. Ask your care team or social worker for more information.

Your Outpatient Care Team

Primary Care Provider (PCP)

Your PCP is usually a family medicine or internal medicine doctor who coordinates care and manages medical issues. This doctor will handle many of your health-related problems, keep your medical history, review your medicines and medical records, and refer you to specialists as needed.

UWMC Rehabilitation Medicine Clinic

If you and your PCP decide you will have your follow-up visits at UWMC’s Rehabilitation Medicine Clinic on 8-South, your first appointment will be made just before discharge. At this visit, you will talk with a physiatrist or nurse practitioner who specializes in rehab issues.

If you have any questions or concerns, call the Rehab Clinic weekdays from 8 a.m. to 5 p.m. The phone number is 206.598.4295. The fax number is 206.598.2813.

Physiatrist (Physical Medicine and Rehabilitation Doctor)

Your physiatrist will oversee your rehabilitation issues, including home health or outpatient therapies, and prescribing medical equipment or medical supplies. This doctor assesses your needs and also may suggest vocational or psychological counseling, as needed.
Specialists

Other special doctors may help manage your ongoing medical issues. These specialists may be urologists, cardiologists, nephrologists, oncologists, surgeons, or others who have been involved in your care. They will work with your PCP and physiatrist.

Physical, Occupational, or Speech Therapists

Ongoing rehab therapies can be provided, either as an outpatient (at UWMC or other facility) or through a home health agency in your home. Your attending physiatrist will advise you on this. They will then oversee your rehab plan of care for 1 month after discharge or until you see an outpatient physiatrist or other doctor who assumes oversight of your outpatient rehab program.

Clinic Nurse

The clinic nurse is a registered nurse (RN) who can help answer your health questions. They also can make sure your PCP gets important information about your healthcare.

Nurse Practitioner

A nurse practitioner (ARNP) is a registered nurse with special training for providing primary healthcare, including many tasks usually done by a doctor. ARNPs can specialize in a certain area of medicine such as rehab or pediatrics.

Nursing Care

Your Inpatient Care Team may prescribe nursing care. This may be through a home healthcare agency or in a specialty clinic such as Wound Care.

Coordinating Your Care

Your attending doctor will talk with your PCP and specialist doctors and provide a discharge summary of the care you received while you were in the hospital.
Choosing Your PCP

If you do not already have a PCP when you are ready to leave the hospital, your Inpatient Care Team can help you find one. If you need help finding a PCP after discharge, you can call any of the University of Washington Physician Network (UWPN) Neighborhood Clinics or the General Internal Medicine Clinic (GIMC) at UWMC - Roosevelt, at 206.598.8750. We encourage you to visit your PCP within 2 weeks of discharge.

Your insurance companies may require a referral if you want coverage for seeing other healthcare providers. These referrals can be made by your inpatient doctor or your PCP.

Requesting Your Medical Records

We advise you to have your medical records sent to your PCP. Most patients ask for this to be done when they are discharged from the hospital.

To see your own records, you may:

- Find them on your MyChart page.
- Visit www.uwmedicine.org. Click on “I want to...” and select “Access medical records and images.”

Medicines (First Prescriptions and Refills)

Your attending physiatrist will give you a full list of your medicines and prescriptions before discharge. Most of your prescriptions will provide medicine to last 1 month. Your PCP and other consulting doctors will receive a copy of your discharge summary, including a full list of the medicines you were prescribed at discharge.

UWMC Prescription Refills

To refill a prescription, use our Refill Authorization Center (RAC), even if you get your medicines through a different pharmacy. If your prescription says it has no refills left, the RAC will take care of getting it refilled.
Refill requests take 48 hours to process. When you need prescription refills:

- If you use an outside pharmacy, call your pharmacy and have them fax us your refill request to 206.744.8538. This is the fastest way to get refills authorized.

- If you want prescriptions to be mailed to you, call the RAC at 206.744.8513. Follow the phone instructions and press the # key to proceed. You will need to provide:
  - Your first name, last name, hospital ID number, and your daytime phone number
  - The name of the medicine and the amount you need
  - The name and phone or fax number of your pharmacy
  - The name of your PCP and clinic

Coumadin (Warfarin)

If you are taking the blood thinner Coumadin (warfarin), either your PCP or an anticoagulation clinic must closely monitor your health. If you like, you can ask the Anticoagulation Clinic at UWMC to handle your blood work and Coumadin prescriptions. To learn more, please call 206.598.4874.

Preventive Care: Staying Healthy Going Forward

Routine preventive health visits you will need to schedule include immunizations (vaccines), health risks and healthy lifestyle counseling, and checkups, tests, and screenings.

Immunizations

Getting the right shots can protect you from various diseases.

Health Risks and Healthy Lifestyle Counseling

Talk with your PCP about:

- The importance of regular exercise, diet, and healthy eating habits
- Smoking
- Drug and alcohol use
- Birth control and sexually transmitted disease
Checkups, Tests, and Screenings

Checkups, tests, and screenings help find health problems early. This can help you make changes in your health habits and get treatment that may save or lengthen your life. Knowing the facts can improve your chances of getting good care. Many screenings can be done by your PCP during your yearly physical exam.

No one screening schedule is right for everyone. Be sure to think about your risk factors. For example, if you have a spinal cord injury, you may have a greater risk for urinary tract infections, high cholesterol, or diabetes. Work with your PCP to plan a schedule that is right for you.

You will need to ask for the screenings and tests you want to have done. Do not assume that your PCP will schedule all of the screenings that you need.

At your yearly exam, talk with your PCP about your overall health, your disability, and other aspects of your life. This helps you build a good relationship with your PCP.

This table shows screenings and when they should be done:

<table>
<thead>
<tr>
<th>When</th>
<th>Healthcare Screenings and Exams</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily</td>
<td>• Skin self-checks (if you are feeling-impaired)</td>
</tr>
<tr>
<td>Monthly</td>
<td>• <em>If you were assigned female at birth:</em> Breast self-exam</td>
</tr>
<tr>
<td></td>
<td>• <em>If you were assigned male at birth:</em> Testicular self-exam</td>
</tr>
<tr>
<td>Yearly</td>
<td>• Visit with PCP, check weight and blood pressure</td>
</tr>
<tr>
<td></td>
<td>• Digital rectal exam after age 40</td>
</tr>
<tr>
<td></td>
<td>• Check for blood in your stool (feces) after age 50 to detect colon polyps that may become cancerous</td>
</tr>
<tr>
<td></td>
<td>• Flu shot</td>
</tr>
<tr>
<td></td>
<td>• <em>If you were assigned female at birth:</em></td>
</tr>
<tr>
<td></td>
<td>- Clinical breast exam after age 40 (sooner if a self-exam is hard to do)</td>
</tr>
<tr>
<td></td>
<td>- Baseline mammogram in your 30s or 40s, annual mammogram beginning in your 40s</td>
</tr>
<tr>
<td></td>
<td>• <em>If you were assigned male at birth:</em> Digital prostate exam and PSA after age 40</td>
</tr>
</tbody>
</table>
When | Healthcare Screenings and Exams
--- | ---
**Every 2 or 3 years** | • Complete blood count with biochemistry study  
• Cardiac risk assessment after age 40  
• Urologic assessment (if you have urinary issues)  
• Assess equipment and posture  
• Functional assessment: transfers, bed mobility, and locomotion (in wheelchair or walking)  
• Full skin check

**Every 5 years** | • Lung capacity (if you have pulmonary impairment)  
• Lipid panel test for cholesterol levels in your blood  
• Eye evaluation after age 40  
• Screening sigmoidoscopy/colonoscopy after age 50 to find colon polyps that may become cancerous  
• Motor and sensory testing  
• Review changes in life situation, including coping, adjustment, life satisfaction

**Every 10 years** | • Tetanus booster  
• Pneumonia vaccine (if you have lung issues)

---

**Solving Problems After Discharge**

After you leave the Rehab Unit, you may need help with solving problems. This table gives resources that can help you resolve some issues that may come up:

<table>
<thead>
<tr>
<th>Issue</th>
<th>What to Do</th>
</tr>
</thead>
</table>
| **Medicine questions or other issues that occur right after discharge** (the night or weekend after discharge) | • For non-urgent questions:  
  - Call 8-North (206.598.4800) and talk with a nurse.  
  - Or, call 206.598.6190 and ask to page the rehabilitation doctor.  
  - If it is an urgent or life-threatening medical issue, **call 911**. |
| **Medicine issue or concern** | Call your PCP, the Rehabilitation Medicine Clinic (if being followed by the clinic), or the doctor who manages that medicine. |
### Issue | What to Do
---|---
Need medicine refill | Call the Refill Authorization Center (206.744.8538) or pharmacy where the prescription was filled.

Outpatient occupational, physical, or speech therapy issue | - If you are currently being seen by OT, PT, or Speech Therapy, call the OT, PT, or Speech Therapist who is providing your care.
- If you are having trouble getting started with your rehabilitation therapy, call your UWMC Rehabilitation attending physiatrist, PCP, or Rehabilitation Medicine Clinic (if being followed by the clinic).
- If you haven’t been seen by your PCP or Rehabilitation Medicine Clinic, have the OT, PT, or Speech Therapist contact your attending physiatrist from 8-North rehab.

Need copies of medical records | Access your records through MyChart or go to www.uwmedicine.org and click on “I want to…” then select “Access medical records and images.”

Home healthcare (OT, PT, Speech Therapy, RN, etc.) concern | Have the home healthcare staff contact your attending physiatrist (who originally prescribed the home healthcare), the Rehab Clinic, your PCP, or a specialist doctor (if it is more than 1 month after discharge and/or you have had follow-up visits after discharge).

---

**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
Helpful Resources
When it’s time to leave the hospital

In this section:
• UW Medicine Resources
• Services in the Seattle Area
• Independent and Supported Living Options
• Modifying Your Home
• Transportation
• Becoming an Employer:
  – Washington State Requirements
  – Federal Requirements
• Guides for Hiring and Managing Caregivers
• Background Checks
• Financial Support
• Return to Work or School
• Recreation and Entertainment
• Smart Devices
• Clothing
• Adaptive Products and Resources
• Sample Forms:
  – Discharge Checklist
  – “Help Wanted” Ad for a Caregiver
  – Caregiver Application
  – Weekly Caregiver Checklist
  – Daily Routine List

As you return to your home and community, you will have many, many questions. This chapter lists resources that other rehab patients and their families have found helpful.

~ Patient Advisor
UW Medicine Patient Resources

The UW Medicine Patient Resource page has several helpful links. Visit www.uwmedicine.org/patient-resources to learn about:

- Directions to the hospital
- Billing and insurance
- Medical records and images
- Support groups and classes
- Resolving a complaint
- Patient rights and responsibilities
- Interpreter services
- Patient education
- Preparing for your visit or stay
- Post-acute care
- International patient program
- Lodging and dining options
- Patient forms
- Pharmacy locations
- Spiritual care, grief and loss services

Services in the Seattle Area

Alliance of People with disAbilities

www.disabilitypride.org

This Alliance helps local people with disabilities live more independent lives. They have 2 independent living centers, in Seattle and Bellevue. They provide information on community services and programs, peer support, and skills training. Areas of help may include housing, attendant care, transportation, employment, assistive technology, and more.
Northwest Regional Spinal Cord Injury System (NWRSCIS)
sci.washington.edu

NWRSCIS is at UWMC - Montlake. It is one of 14 model systems in the U.S. for treating spinal cord injuries (SCI). The NWRSCIS website is mainly for those with spinal cord injuries, but people with other conditions may also find it helpful. Forums and streaming videos cover employment, managing your health, transportation, ageing, dating, remodeling your home for wheelchair use, and many other topics. The archive of past newsletters is a great resource, too. NWRSCIS also has a peer mentoring program which matches newly injured patients with a peer for the same gender, injury level, and age.

Independent and Supported Living Options

- **Skilled nursing facilities**: These community facilities are licensed to provide around-the-clock skilled nursing care and skilled therapy services. A list of skilled nursing facilities by city, state, or zip code, along with information about staffing and quality measures, is online at [www.medicare.gov](http://www.medicare.gov).

- **Adult family homes**: These single-family homes are licensed as care facilities for up to 6 residents. They are staffed 24 hours a day. Care level and quality can vary widely, so ask questions and visit the homes you are interested in to make sure your needs can be met. Adult family homes accept Washington Apple Health and private pay. Visit the DSHS website at [www.dshs.wa.gov](http://www.dshs.wa.gov) or the Sound Generations at [soundgenerations.org](http://soundgenerations.org) to learn more.

- **Assisted living**: These communities offer apartment living with part-time help with managing medicines, bathing, and other activities of daily living (ADLs). Most assisted living communities have a minimum age of 55. Assisted living can be paid for by Washington Apple Health or private funds.

- **Subsidized housing**: Most communities have subsidized housing programs for people with disabilities. In the greater Seattle area, there are several Housing Authorities, each with its own application process and waiting list:
- **Department of Housing and Urban Development (HUD)** runs a federal housing program for home buyers, home owners, and tenants in multi-family and single-family housing.

- **Section 8** is a voucher program that allows the voucher holder to get housing in any building that accepts Section 8 subsidy. The voucher can also be transferred to another city or state if the resident moves.

**Modifying Your Home**

Many people need to make structural changes to their home for them to live there independently after rehab. Watch the video “Home Modification after Spinal Cord Injury” at [http://sci.washington.edu/info/forums/reports/home_mod_07.asp](http://sci.washington.edu/info/forums/reports/home_mod_07.asp) for ideas on how to make your home more accessible.

The video is useful for people with other disabling conditions, too. The webpage also lists many other helpful resources.

**Transportation**

**Free Transportation with Washington Apple Health**

If you have Washington State Medicaid, you may be eligible for free on-emergency transportation. To learn more, visit [www.hca.wa.gov/billers-providers-partners/programs-and-services/transportation-services-non-emergency](http://www.hca.wa.gov/billers-providers-partners/programs-and-services/transportation-services-non-emergency) or send an email to hcanemtttrans@hca.wa.gov.

**Regional Transit Buses**

All buses on the regional transit systems (Metro, Community Transit, and Sound Transit), from Tacoma to Everett, are very accessible. The drivers are usually very polite to people with disabilities. All transit systems have different programs to support your transportation needs.

- **Metro Bus Service:**
- **Community Transit**: [www.communitytransit.org](http://www.communitytransit.org)
- **Sound Transit**: [www.soundtransit.org](http://www.soundtransit.org)

**Shuttles, Taxis, Rideshares, and Rentals**

There are several options to help with transportation in the community.

- Shuttle services such as Shuttle Express, taxi services, and rideshares have accessible transportation options. Wheelchair-accessible shuttles and taxis may be an option. **Be sure to tell them that you need a wheelchair-accessible taxi or shuttle when you call to schedule.**

- Ride shares such Lyft and Uber can accommodate foldable mobility devices such as a foldable wheelchair, walker, scooter, or canes and crutches. **Be sure to tell the driver how you would like them to help you and how to fold and store your mobility device.**

- HopeLink is a non-profit organization that provides several transportation services. Visit [www.hopelink.org/need-help/transportation](http://www.hopelink.org/need-help/transportation) to learn more.

- Local dealers of accessible vehicles may have a small number of rentals. These may be costly, but are worth it if you want to do some traveling. Absolute Mobility Center offers wheelchair-accessible van rentals for healthcare appointments, vehicle repairs, vacations, and special occasions. Visit [www.absolutemobilitycenter.com](http://www.absolutemobilitycenter.com) to learn more.
Becoming an Employer

If you will be hiring a caregiver, these resources are essential. You will need to get a business license and meet other state and federal requirements for being an employer.

Washington State Requirements

Department of Licensing Business Licensing Service
https://dor.wa.gov/open-business

Click on “Start a Scenario.” Then select “Care Giver” as your business activity. The activities are listed in alphabetical order. You can either scroll through several pages to find the listing or type “care giver” into the “Filter” field.

Employment Security Department (ESD)
www.esd.wa.gov

Once you hire a caregiver, you must file state employment taxes every quarter. ESD can help you with a Master Business Application and guide you through the new employer process. They will issue you a Unified Business Identification (UBI) number. This is like a Social Security number for your domestic help business.

Department of Labor and Industries
www.lni.wa.gov

Contact this department if you need or are required to carry Worker’s Compensation coverage.

Department of Social and Health Services
www.dshs.wa.gov/newhire

You must file a New Hire Report with the DSHS when you hire a new or returning employee.
Federal Requirements

Employer Identification Number


Apply for your federal Employer Identification Number (EIN) online, and you will receive your EIN right away. You can then download, save, and print your EIN confirmation notice.

Internal Revenue Service

- You must pay Medicare, Social Security, and Federal Unemployment Tax (FUTA) quarterly as a sole proprietor/individual taxpayer with your 1040 Estimated Tax:

- Report household employee wages on your annual IRS return:

- Report household employee wages to the employee with a W-2 form and to the government with a W-3 form in January after the year of employment.
  - Instructions for Forms W-2 and W-3 are online at www.irs.gov/pub/irs-pdf/iw2w3.pdf.
Online Guides for Hiring and Managing Caregivers

- **Personal Caregivers: Tips, Tricks and Tales from Individuals with Spinal Cord Injury:** People with spinal cord injuries share their tips for finding, hiring, and managing personal caregivers. Visit http://sci.washington.edu/info/forums/reports/caregivers.asp to watch the video or read the report. The tips are also helpful for people with other disabling conditions.

- **Personal Care Assistants: How to Find, Hire and Keep Them:** https://craighospital.org/resources/personal-care-assistants-how-to-find-hire-keep

- **Personal Care Assistance: How Much Help Should I Hire?:** https://craighospital.org/resources/personal-care-assistance-how-much-help-should-i-hire

- **Managing Personal Assistants: A Consumer Guide:** A free 70-page guide by Paralyzed Veterans of America (PVA). Download the guide or order a printed copy at https://pvasamediaprd.blob.core.windows.net/prod/libraries/media/pva/library/publications/persasstfc6d.pdf. There is a shipping charge added for printed copies.

- **Care.com:** This online service helps you find, manage, and pay for caregiving services. They can help with background checks, household taxes, and payroll. Visit www.care.com to learn more.

Background Checks


- **Employer Info Source** is a private company that provides several screen and background verification packages. Visit http://employersinfosource.com/services to learn more.
Financial Support


Financial Support through COPES

COPES (Community Options Program Entry System) is a program of the Washington State Department of Social and Health Services (DSHS) that pays for personal care and other services for eligible clients in their own homes or in residential facilities. It is designed for people who, without this financial support, would need to be in nursing homes.

- Eligibility for COPES is based on health, disability status, and financial need. Visit [www.washingtonconnection.org/home](http://www.washingtonconnection.org/home) to learn more.


Return to Work or School

Work with your medical team to determine a return to work or school plan. Here are some services you may find helpful:

- **Rehabilitation counselors** can help provide resources, career guidance or help set up volunteer work. Rehabilitation counseling is part of the rehabilitation outpatient clinic at UWMC - Montlake.

- **Department of Vocational Rehabilitation (DVR)** is a statewide resource that assists people with disabilities prepare for, secure and maintain employment. Visit [www.dshs.wa.gov/dvr/about-dvr](http://www.dshs.wa.gov/dvr/about-dvr) to learn more.
Recreation and Entertainment

There are many discounted or free services for people with disabilities:

- **The Flash Card:** This card is issued by the City of Seattle. It provides free or discounted prices to Seattle area retail stores, services, arts, entertainment, tourism, and more. Visit [www.seattle.gov/agefriendly/about/discount-program](http://www.seattle.gov/agefriendly/about/discount-program) to learn more.

- **The Access Pass:** This card is issued by the National Parks Service. It is a lifetime pass for U.S. citizens or permanent residents with permanent disabilities. The card allows the pass holder and 3 adults to enter the parks for free. Visit [www.nps.gov/fees_passes.htm](http://www.nps.gov/fees_passes.htm) to learn more.

- **Outdoors for All:** This program allows people with disabilities to continue an active life year-round. Outdoor activities with this group include alpine skiing, white water rafting, hiking, water skiing, other water sports, weekend excursions, rock climbing, kayaking, and canoeing. Visit [www.outdoorsforall.org](http://www.outdoorsforall.org) or call 206.838.6030 to learn more.

- **Washington Trails Association: Accessible Trails:** Visit these websites to learn about accessible trails in Washington state:
  - [www.wta.org/trail-news/signpost/accessible-trails](http://www.wta.org/trail-news/signpost/accessible-trails)
  - [www.parks.wa.gov](http://www.parks.wa.gov)

- **Footloose Sailing:** A sailing program for people with all types of disability. Visit [www.footloosesailing.org](http://www.footloosesailing.org) to learn more.

- **Movie theatres:** Although this is not widely known, many movie theatres offer free entry for your caregiver or assistant. Just ask at the box office if they offer this service.
• **Plays, symphony, sporting events, concerts, and more:** Go out and have some fun! Most of these public facilities have good access for people with disabilities. Staff are usually very helpful and you may get the best seats in the house! Some places offer free admission for your caregiver or assistant. Ask at entry if they offer this service.

• **AccessibleGo:** This website provides travel resources as well as an online community to share accessible travel resources. Visit [https://accessiblego.com/home](https://accessiblego.com/home) to learn more.

• **Seattle Adaptive Sports (SAS):** The mission statement of SAS is to enhance and promote the well-being of physically challenged individuals by giving them the opportunity to participate and compete in athletic and recreational activities. Visit [www.seattleadaptivesports.org](http://www.seattleadaptivesports.org) to learn more.

• **Wheelchair yoga and meditation:** There are many online resources and videos of seated yoga classes. You can also ask your local yoga centers if they have a seated yoga class.

**Smart Devices**

Technology can be a great tool. It can help you be productive and efficient. We talk a lot about how technology can help you throughout this *Rehab and Beyond* manual, but here are some basic tips:

• **Cell phones, tablets, and wearable technology:** Voice controls, such as Siri or Alexa, can help you call or text anyone. Wearable technology, such as a smartwatch, can act as a medical alert and allow you to easily call 911 in an emergency.

• **Smart home devices:** Smart devices can help you manage items around your house such as your TV, thermostats, and lights. A website called “Smart Homes Made Simple” has resources including a self-assessment to help you get started. Visit [https://smarthomesmadesimple.org](https://smarthomesmadesimple.org) to learn more.
• Technology can also help you do household tasks. Some examples include robot vacuums, electronic pet feeders, electronic door openers. Sites such as Wirecutter or Consumer Reports provide reviews of products to help you choose the best product for you and your needs.

• **WATAP:** The Washington Assistive Technology Act Program (WATAP) provides resources and services to help you choose and use assistive technology, including smart devices. Visit [https://watap.org/services](https://watap.org/services) to learn more.

**Clothing**

Many websites offer clothing and patterns designed for people with disabilities. Try searching online for adaptive or accessible clothing. Facebook groups and other online communities also offer many resources.

**Adaptive Products and Resources**

• **Makers Making Change:** This website connects makers to people with disabilities who need assistive technologies. Visit [www.makersmakingchange.com](http://www.makersmakingchange.com) to learn more.

• **Adaptive computer products:** This website provides links to other websites and books. Visit [www.makoa.org/computers.htm](http://www.makoa.org/computers.htm) to learn more.

• **ErgoMart:** Office and computer products. Visit [www.ergomart.com](http://www.ergomart.com) to learn more.

• **InfoGrip:** Assistive technology hardware and software. Visit [www.infogrip.com](http://www.infogrip.com) to learn more.
### Sample Discharge Checklist, page 1

<table>
<thead>
<tr>
<th>Service or Equipment</th>
<th>UWMC Resource (person or service)</th>
<th>Community Resource</th>
<th>Commercial Resource</th>
<th>Cost</th>
<th>Notes and Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Equipment</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Supplies</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Prescription Items</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Over-the-Counter Items</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Sample Discharge Checklist, page 2

<table>
<thead>
<tr>
<th>Service or Equipment</th>
<th>UWMC Resource (person or service)</th>
<th>Community Resource</th>
<th>Commercial Resource</th>
<th>Cost</th>
<th>Notes and Comments</th>
</tr>
</thead>
</table>

**Home Changes (such as doorways, floor transitions, type of flooring, bed height)**

<table>
<thead>
<tr>
<th>Service or Equipment</th>
<th>UWMC Resource (person or service)</th>
<th>Community Resource</th>
<th>Commercial Resource</th>
<th>Cost</th>
<th>Notes and Comments</th>
</tr>
</thead>
</table>

**Structural Changes (such as ramps)**

<table>
<thead>
<tr>
<th>Service or Equipment</th>
<th>UWMC Resource (person or service)</th>
<th>Community Resource</th>
<th>Commercial Resource</th>
<th>Cost</th>
<th>Notes and Comments</th>
</tr>
</thead>
</table>

**Home Automation/Smart Home Devices (such as light switches, door openers, thermostat, fan, HVAC controls)**

<table>
<thead>
<tr>
<th>Service or Equipment</th>
<th>UWMC Resource (person or service)</th>
<th>Community Resource</th>
<th>Commercial Resource</th>
<th>Cost</th>
<th>Notes and Comments</th>
</tr>
</thead>
</table>

**Safety Measures (such as easy access to communication devices, first aid kit)**

<table>
<thead>
<tr>
<th>Service or Equipment</th>
<th>UWMC Resource (person or service)</th>
<th>Community Resource</th>
<th>Commercial Resource</th>
<th>Cost</th>
<th>Notes and Comments</th>
</tr>
</thead>
</table>
## Sample Discharge Checklist, page 3

<table>
<thead>
<tr>
<th>Service or Equipment</th>
<th>UWMC Resource (person or service)</th>
<th>Community Resource</th>
<th>Commercial Resource</th>
<th>Cost</th>
<th>Notes and Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Daily Routine</strong> (such as type of bed linens best for you, equipment for bathing, eating)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Transportation</strong> (such as type of vehicle, height of vehicle, community transport options)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Transition of Care from Hospital to Home</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Follow-up Services</strong> (such as healthcare visits, outpatient therapy, vocational rehab therapy)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Other Resources</strong> (such as DSHS, community resources)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Sample “Help Wanted” Ad for a Caregiver

Help Wanted: Aide, Caregiver

Days:  (List days you need help.)
Hours:  (List hours you need help.)
Area:  (Your neighborhood name.)
Contact:  (List name, numbers, email, etc. Include best times to call if phoning.)

Employment Opportunity

Part-time morning personal health aide for active adult male quadriplegic with spinal cord injury. I was injured in 2002, have a positive attitude and am healthy, but need morning help in my private residence. There are no pets or other distractions. This is not a live-in position.

Duties

Help with bathroom routine, cleaning of urological supplies, skin inspection, range of motion, dressing, cooking, exercise program, laundry, light housecleaning. No transfers or heavy lifting.

Desired Assistant Profile

Speaks English. A person who gets satisfaction from doing their job well. Punctual, dependable, self-directed, nonsmoking. Positive attitude and sense of humor. Ability to work quickly and efficiently. Reliability is very important; unscheduled absences are unacceptable.

Washington state driver’s license and reliable automobile transportation required. Experience working with male spinal cord injury desired, but I am willing to train. Seeking an individual who wants one or more years’ work. References, please.

Pay

Competitive hourly rate; determined individually; paid weekly.

Orientation and training with another current employee is typically provided for 3 days. Those orientation days will be paid after 30 days employment.

$_____ extra for New Year’s Day, Memorial Day, July 4, Labor Day, Thanksgiving Day, Christmas Day; also for emergency coverage of another shift.

Social Security and Medicare taxes withheld and employer’s share paid. Aide pays own federal income tax, which will not be withheld.

Bonus or raises depend on performance, punctuality, absenteeism, length of employment, compatibility, and general attitude.

Other Position Also Needed

Fill-in coverage from time to time, as needed. Job duties and qualifications same as above.
Sample Caregiver Application, page 1

Name _______________________________ Social Security #:______-_____-_______ Date: ___________

Address:____________________________________________________________________________________

Home Phone: ___________________ Cell Phone: _________________________ Email: _____________________

Best way to reach you: _______________________________________ When: _____________________________

Are you eligible to be employed in the United States? _______________ Are you over 18? ________________

Are you able to meet the attendance requirements? ________________ Date available to start: ______________

Days of week available: _______________________________________ Length of employment desired: ______________

Days and/or dates not available:___________________________________________________________________

Have you been an attendant before? ________ Number of years? ______ Work with male quadriplegic? ________

License, CNA, etc. Certification number:________________________________________________________________

Are you a licensed personal care business? __________________________________________________________

Driver’s license number: _______________________________ State: ______ Car license plate: _______________

Driving record, describe: _______________________________ Auto insurance company: ____________________

Have you ever pled “Guilty,” “No Contest,” or been convicted of a felony? _________________________________

If yes, please provide date, location, details, and explanation: ___________________________________________

Smoker: □ Yes □ No   Physical limitations, allergies, or medicines that may affect your work: ______________

Do you have medical insurance? _________ If yes, what? _____________________________________________

Career goal:___________________________________________________________________________________

Why do you want this job?________________________________________________________________________

Education  List schools attended; begin with most recent.

School: _____________________________________________ Degree/Area of study _______________________

School: _____________________________________________ Degree/Area of study _______________________

School: _____________________________________________ Degree/Area of study _______________________

Summarize any special training that may relate to this job. _____________________________________________

_____________________________________________________________________________________________

_____________________________________________________________________________________________

_____________________________________________________________________________________________

_____________________________________________________________________________________________
Sample Caregiver Application, page 2

Personal References I May Contact

Name: _________________________________ Relationship: __________________ How long? ________________
Address: _____________________________________________________________ Phone: ___________________

Name: _________________________________ Relationship: __________________ How long? ________________
Address: _____________________________________________________________ Phone: ___________________

Employment History

Please list your most recent employer first.

Employer: ___________________________________ Phone: _____________________________ May I contact? _____________
Supervisor: __________________________________ Phone: _____________________________ May I contact? _____________
Location: ___________________________________ Start date: __________________________ End date: ________________
Job title: ____________________________________ Salary or wage: _______________________ Hours: ________________
Job duties: _________________________________________________________________________________________________
__________________________________________________________________________________________________________
Reason for leaving: __________________________________________________________________________________________

Employer: ___________________________________ Phone: _____________________________ May I contact? _____________
Supervisor: __________________________________ Phone: _____________________________ May I contact? _____________
Location: ___________________________________ Start date: __________________________ End date: ________________
Job title: ____________________________________ Salary or wage: _______________________ Hours: ________________
Job duties: _________________________________________________________________________________________________
__________________________________________________________________________________________________________
Reason for leaving: __________________________________________________________________________________________

Employer: ___________________________________ Phone: _____________________________ May I contact? _____________
Supervisor: __________________________________ Phone: _____________________________ May I contact? _____________
Location: ___________________________________ Start date: __________________________ End date: ________________
Job title: ____________________________________ Salary or wage: _______________________ Hours: ________________
Job duties: _________________________________________________________________________________________________
__________________________________________________________________________________________________________
Reason for leaving: __________________________________________________________________________________________
Sample Caregiver Application, page 3

Employer: __________________________ Phone: __________________________ May I contact? ____________

Supervisor: _________________________ Phone: _________________________ May I contact? ____________

Location: __________________________ Start date: ______________________ End date: __________________

Job title: __________________________ Salary or wage: __________________ Hours: __________________

Job duties: _____________________________________________________________________________

Reason for leaving: _______________________________________________________________________

1. Do you have experience doing bowel programs? _____________________________________________
2. Do you have experience doing range of motion? ____________________________________________
3. Do you have experience doing skin inspection? ____________________________________________
4. Give examples of foods or meals you are comfortable cooking: ______________________________
5. Please list several of your skills. __________________________________________________________
6. List a few of your personality traits. _______________________________________________________ 
7. Are you pet friendly? _________________________________________________________________
8. Are you talkative or on the quiet side? ____________________________________________________
9. Do you consider yourself patient? _______________________________________________________
10. Are you detail-oriented? __________________________________________________________________
11. What is your comfortable work pace? _____________________________________________________
12. Are you comfortable doing light housework? _____________________________________________
13. What do you do to keep on schedule? ____________________________________________________
14. What motivates you? ___________________________________________________________________
15. What adds to your job satisfaction? ______________________________________________________
16. What lowers your job satisfaction? _______________________________________________________
17. How do you handle instruction and constructive criticism? _________________________________
18. How do you like to receive feedback? _____________________________________________________
19. How do you communicate your expectations? _____________________________________________
20. What kinds of things irritate you? _______________________________________________________
21. Is it easy for you to accept an apology? _________________________________________________
22. How many times were you late for work in the last year? _________________________________
Sample Caregiver Application, page 4

23. How many days of scheduled work did you miss in the last year? ____________________________________________

24. I need help every morning. Are you comfortable driving in the snow? ________________________________

25. Do you have plans, such as vacations, holidays, etc., that will conflict with this position? (list) ________________

26. Are you available and willing to have me call you for substitution work? ________________________________

27. Will you travel for a few days if the circumstances are satisfactory? ________________________________

28. What has been the best part of working in home healthcare for you? ________________________________

29. What has been the worst part of working in home healthcare for you? ________________________________

30. What salary or wage do you desire? ___________________________________________________________

29. Give an example of how you continue to educate yourself. __________________________________________

30. What is the most important lesson you have learned working with clients? ____________________________

Applicant Release Form

I certify that the information I have provided is true and complete. I authorize you to contact references, employers, public agencies, licensing authorities, and other entities as needed to verify the accuracy of the information I provided. I understand that if hired, I must provide proof of identity and legal authority to work in the United States. I understand that information provided by me that is false, incomplete, or misleading will be sufficient cause for termination of employment.

I have read, understand, and accept the statement above.

Print Your Name ________________________________________________________________________________

Signature ________________________________  Date ________________________________
## Sample Caregiver Weekly Checklist

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Hours of sleep</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td># of hours</td>
<td>hrs</td>
<td>hrs</td>
<td>hrs</td>
<td>hrs</td>
<td>hrs</td>
<td>hrs</td>
<td>hrs</td>
</tr>
<tr>
<td>Urine: C=clear, D=dark</td>
<td>C, D</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bowel movement</td>
<td>S, M, L, XL</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BM: F=formed, L=loose</td>
<td>F or L</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peri-care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shower</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range of motion</td>
<td>Y/N</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Make breakfast</td>
<td>Y/N</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assist with</td>
<td>Y/N</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Make lunch</td>
<td>Y/N</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Make dinner</td>
<td>Y/N</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assist with</td>
<td>Y/N</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assist with exercises</td>
<td>min</td>
<td>min</td>
<td>min</td>
<td>min</td>
<td>min</td>
<td>min</td>
<td>min</td>
</tr>
<tr>
<td>Vacuum dining room, traffic areas</td>
<td>as needed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>as needed</td>
</tr>
<tr>
<td>Vacuum house</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vacuum sofas (every 2 weeks)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clean bathrooms</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wash shower curtain (1 x month)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Load/unload dishwasher</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shopping</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sweep doorways (other as needed)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mop vinyl floors</td>
<td>vinyl</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Water plants (fertilize every 2 weeks)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dusting - bedroom</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dusting throughout house</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laundry</td>
<td>old towels</td>
<td>old towels</td>
<td>bath towels</td>
<td>clothes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laundry, bedding</td>
<td>bedding</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feed animals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Print your initials clearly</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hours worked</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td># hours</td>
<td>hrs</td>
<td>hrs</td>
<td>hrs</td>
<td>hrs</td>
<td>hrs</td>
<td>hrs</td>
<td>hrs</td>
</tr>
</tbody>
</table>

*(Shaded areas indicate a minimum frequency; mark when completed)*

**General Notes**  
(Enter the date, write notes as needed, then initial your entry)
Sample Daily Routine List

Morning Caregivers:

7:45 to 8:00 .......... Wake up
8:00 to 8:45 .......... Transfer to toilet, toileting
8:45 to 9:45 .......... Shower and get dressed (Monday, Wednesday, and Friday)
8:45 to 9:15 .......... Put on pants, socks, and shoes
9:15 to 9:30 .......... Transfer to wheelchair
9:30 to 10:00 .......... Eat breakfast, take medicines
10:00 to 10:30 ...... Wash face, brush teeth, comb hair, put on shirt
10:30 to 11:30 ...... Do exercises from my wheelchair

Afternoon Caregivers:

12:30 to 1:15 ...... Eat lunch, take medicines
1:15 to 5:00 .......... Free time, appointments, rest in bed if needed

Evening Caregivers:

5:00 to 6:00 .......... Eat dinner, take medicines
6:00 to 9:00 .......... Free time
9:00 to 9:30 .......... Wash face, brush teeth, undress
9:30 to 9:45 .......... Transfer to bed

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 UWMC’s Inpatient Rehab Unit, call 8.4800 from your bedside phone. From outside the hospital, call 206.598.4800.

After discharge, call your primary care provider or UWMC’s Rehabilitation Clinic: 206.598.4295