

PREPARING TO TRANSITION HOME



First Edition 2019

**This booklet is a joint production of Craig Hospital and the
Christopher & Dana Reeve Foundation's Paralysis Resource Center.
Hollister has generously provided financial support.**

**This guide has been prepared based on scientific and professional literature.
It is presented for the purpose of education and information; it should not be construed
as medical diagnosis or treatment advice. Please consult a physician or appropriate
healthcare provider for questions specific to your situation.**

Credits

**Written by: Bevin Peterson, RN, MS, CRRN, Craig Hospital
Produced and Edited by: Patricia E. Correa, Sheila Fitzgibbon, Bernadette Mauro,
Christopher & Dana Reeve Foundation
Editorial Consultant: Linda M. Schultz, PhD, CRRN
Photos: Courtesy of Craig Hospital, page 12 photo courtesy of Permobil**

Christopher & Dana Reeve Foundation

**636 Morris Turnpike, Suite 3A
Short Hills, NJ 07078
(800) 539-7309 toll free
(973) 379-2690 phone
ChristopherReeve.org**

Craig Hospital

**3425 S. Clarkson St.
Englewood, CO 80113
(800) 247-0257
(Nurse Advice Line)
CraigHospital.org**

CONTENTS

- 
- 1** Medical Care After Discharge
 - 6** Home Health/Caregiving
 - 7** Medical Must Know
 - 15** Home Modifications
 - 16** Benefits and Financial Resources
 - 18** Transportation
 - 19** Important but Easy to Overlook
 - 22** Getting Organized
 - 22** Your Social Self
 - 23** Know Your Rights
 - 23** Employment and Education
 - 24** Technology
 - 25** Timeline Chart
 - 28** Notes

INTRODUCTION

Discharge from inpatient rehabilitation is a transition from hospitalization back to the community. However, it does not mean the end of recovery. Whatever your next step is, you should begin working on a discharge plan within the first few days of your inpatient admission. Rehabilitation facilities and hospitals have a discharge planner on staff. There is no cost to inpatients to use their services.

After finding out you have a spinal cord injury or other type of paralysis, you may not know what questions to ask in preparation for your return home. The following booklet will give you some ideas of what to look into before leaving the hospital.

- Continued medical care and ongoing physical and/or occupational therapy
- The type of supervision and assistance that you may need at home
- Transportation
- Accessibility and equipment needs
- Funding resources
- A plan to return to your daily activities

At the end of this booklet, there is a chart of tasks that may apply after a spinal cord injury or other type of paralysis. It can be used as a checklist in preparation for your transition back to the community.

MEDICAL CARE AFTER DISCHARGE

Primary Care Physician (PCP)

It is important that you have a primary care physician to help with the medical care you need. When evaluating physicians, make sure that they are capable of and comfortable with taking care of a person with a spinal cord injury. Many physicians have never had the opportunity to take care of someone with a spinal cord injury and may not be aware of all of your medical needs. Offices are not always set up in a way that makes getting care easy for a person in a wheelchair. When choosing a physician, it will be helpful to have a list of questions you want to ask them.

PCP ACTIONS

- ✓ *Contact your prior PCP to check if they are willing to work with your new needs.*
- ✓ *If referrals are needed, is your PCP comfortable and willing to manage care and write referrals to specialists?*

Specialists

Your medical needs may require physicians that specialize in certain parts of the body, such as a pulmonologist that specializes in a person's respiratory needs. Before discharge from the hospital, make sure that you have an appointment set up with all of the specialists you will need. During your transition home, you might forget to make these appointments if you wait to schedule once you are home.

Mental Health

Dealing with a spinal cord injury can be stressful and may cause you to experience emotions or feelings that you are not sure how to manage. Having someone to talk to may help. A counselor is trained to help you work through these emotions and feelings. When looking for a counselor it will be important to find out if they have an office that is accessible. Some may even come to your home.



Occupational Therapist (OT) / Physical Therapist (PT)

Some people will have occupational therapy and physical therapy after they go home. This decision is usually based on a person's needs after discharge and whether or not their insurance covers outpatient therapy. If you are going to have therapy, encourage your hospital therapists to help you create goals and, if possible, have them talk to your new therapists.

SPECIALIST PROVIDER ACTIONS

Ask your inpatient physician or PCP if you need to see any of these specialists. Remember to get any necessary referrals and to check your insurance coverage.

- ✓ *Urologist*
- ✓ *Neurologist*
- ✓ *Physiatrist*
- ✓ *Counselor, Psychiatrist, or Social Worker*
- ✓ *Neurosurgeon*
- ✓ *Pulmonologist*
- ✓ *Podiatrist*
- ✓ *Wound Care*
- ✓ *OB/GYN*
- ✓ *PT/OT*

ACCESSIBILITY CONSIDERATIONS

- ✓ *How accessible is their office?*
- ✓ *Will you be able to move around the office easily in a wheelchair?*
- ✓ *Is there an exam table that can be lowered so you can transfer onto it?*
- ✓ *If not, is transferring equipment available?*
- ✓ *If not, how will they perform a physical assessment?*
- ✓ *Is there disabled parking available?*

Durable Medical Equipment (DME)

Having paralysis may mean you are going to need special equipment to help you with activities of daily living (ADLs). The first step is knowing what you are going to need. Your physical and occupational therapists can help you identify these needs.

Some of these items may include:

- Wheelchair
- Commode chair/shower chair
- Stair lift
- Transfer lift or board

There is adapted equipment that can be purchased which may help you increase your independence.

Other things to think about include:

- What does your insurance cover?
- Who can help you purchase the equipment?
- Finding a supplier
- Who can help you put the equipment together?
- How to troubleshoot problems with equipment
- Check out equipment loan closets before you purchase the equipment

Personal Care Supplies

Before discharge, work with your medical team to help you determine supplies you may need such as respiratory, skin, dietary, bedding, or bowel/bladder supplies.

QUESTIONS TO THINK ABOUT

- ✓ *What supplies will you need?*
 - *Catheter supplies*
 - *Wound care supplies*
 - *Non-latex gloves*
 - *Bowel care supplies*
 - *Other supplies: _____*
- ✓ *When and how will they be ordered?*
- ✓ *How will they be delivered and paid for?*
- ✓ *How do you re-order?*

Medications

At discharge your physician will write prescriptions for all of the medications that will be needed. Before the discharge day, you should work with the nursing staff or pharmacy to:

- Develop a plan for obtaining your medications after you leave the hospital. This may include sending prescriptions to the next rehabilitation center or selecting a pharmacy where you would like to obtain medications. Using one pharmacy for all your medications will help prevent medication errors.
- Understand your medications: what they are for, doses, times of the day they should be taken, duration of therapy, side effects, and how to manage them. This may also include discussions about drug, alcohol, and food interactions.

- Understand what medications are covered by insurance and what will be required when you obtain them outside the hospital.
- Plan for where you are going to store your medications. They should be kept in one place and out of reach of young children. Don't forget to consider refrigerated medications.
- Learn how to sort and fill a pillbox to make taking medications on time easier. At home this can be done by yourself or with a caregiver.
- Create a plan to remember to take your medications. For example, there are apps available to help set reminders on your phone.
- If you take injectable medications, find out how to properly dispose of needles in your community. Call your local health department for disposal information.

Long Term Care (LTC) vs. Home Care



There are many things to think about when deciding where to go after discharge. A big consideration is how much care you are going to need. Another thing to consider is how much help insurance will pay for or how much you can afford to pay yourself. Each person's situation is unique. Your inpatient rehabilitation team can help you identify needs that will be specific to you. Some things to consider are:

- How much help you will need to transfer in and out of bed?
- Will anyone in your family be able to help you with physical needs or would you need supplemental assistance? Will you need to hire caregivers to help?
- Will you need assistance with your activities of daily living?
- Do you have a support network (family, friends)?
- Can you be home alone? (People on mechanical ventilation may need 24/7 support)

Which Caregiver is Right for You?

Insurance coverage and finances play a big role in how much assistive care a person gets when they go home. If you are thinking about caregivers, it is important for you to consider how much and what care you are going to need. Family and friends may be able to help prepare food, while a nurse may be required to provide medical care. If you need help getting dressed and out of bed, you may need to hire a certified nursing aide (CNA) or your family may be able to help. You will want to have these people in place before going home.

Every state has different rules about what type of care can be provided at each level of licensing. When hiring through a local healthcare agency, that agency will identify the appropriate skill level needed. The following list provides some ideas of what type of person can provide care.

- Registered Nurse (RN) – medication management, wound care, assessments, catheter changes
- Certified Nursing Aide (CNA) – dressing, bathing, getting out of bed, meals, feeding
- Family/Friends – meals, feeding, cleaning, laundry, grocery shopping, picking up mail*

* *Note: These may be considered maintenance care and may not be covered by insurance.*



Therapy After Discharge

After discharge, and depending on your insurance benefits, services provided by physical and occupational therapists may be provided at home for a period of time. These services are temporary and depend on medical necessity, level of injury, and ability to eventually go to an outpatient therapy center.

Other types of therapy may include local recreation centers with accessible equipment, pools, activity-based therapy in gyms or rehabilitation centers, personal trainers, and adaptive sports or recreation programs.

Having a spinal cord injury affects more than just your ability to walk. Maintaining overall health is extremely important.

When to go to the doctor:

There are many reasons a person should go see a doctor. If you are unsure about going to the doctor or not, it is always best to call them and have them help you decide.

When you have a chronic illness such as spinal cord injury or paralysis, you may need to visit your doctor often. Make it a practice to ask your doctor when they recommend returning if you do not improve or feel better. Do not assume that just because you are on antibiotics that you will get better. Some of the health issues below can cause sepsis (blood infection) if not treated properly. Sepsis is very serious and can lead to death if not treated immediately. Many of the topics below include a list of signs and symptoms that signal you might need to go to the doctor.

Bladder

The bladder is part of the urinary tract system. This system is responsible for removing toxins and waste products from the blood by the kidneys. This waste is then sent to the bladder to be emptied out of the body. Without properly functioning kidneys, the body cannot get rid of these toxins which can ultimately lead to death. It is extremely important to take care of this system.

The best way to care for your urinary tract system is by emptying the bladder and keeping the amount (volume) of urine in the bladder low. With paralysis, a person may no longer get the feeling that they need to empty their bladder. This creates a high risk for urine backing up from the bladder into the kidneys which may cause permanent damage.

Before you go home from the hospital, you need to know how you are going to empty your bladder and therefore take care of your urinary tract system.

THINGS TO THINK ABOUT

- ✓ *Do you need to use a catheter?*
- ✓ *How much help are you going to need to empty your bladder?*
- ✓ *What non-latex supplies will you need at home?*
- ✓ *Where will you get your non-latex supplies?*
- ✓ *How will you order your non-latex supplies?*
- ✓ *Have your family/caregivers been trained about your bladder management?*
- ✓ *Do you know the signs and symptoms of urinary tract infections (UTIs)?*

When to go to the doctor for bladder issues:

- Fever/temperature of 100.4 degrees or higher
- Chills
- Dark colored, cloudy, or sediment-filled urine
- Blood in urine
- Foul odor or smell to urine
- Nausea
- Pain with urination (if you have sensation in this area)
- Frequent need to urinate (if you have sensation in this area)
- Pain in lower back (if you have sensation in this area)
- Increased spasms

For more information, see the Reeve Foundation Bladder Management booklet www.ChristopherReeve.org/BladderToolkit

Bowel

Before a spinal cord injury, you probably did not put much thought into taking care of your bowels. Your body did all the work automatically. You eat food, it goes into your stomach, the food is digested, sent through the intestines, and eventually becomes stool. Once the stool is ready to come out, you feel that it is time to go to the bathroom.

After a spinal cord injury, things are still working but may be moving slower. Also, you may not be able to feel when you need to go, and/or you may not be able to use the muscles needed to push stool out. Because of this, you will need to have a bowel program to prevent constipation and accidents. A bowel program should be done at the same time of day and may include the use of a suppository and digital stimulation. During a bowel program, the bowel tissue is being stimulated by the suppository. The stimulation sends a message that says you need to empty your bowels, then the stool moves down. Digital stimulation is done to relax the rectal sphincter and allow stool to come out.

Some people will need a caregiver to assist with their bowel management program. Every person will have individual needs, so it is important that you educate your caregiver about your needs. It is essential that you are able to direct and manage your own care verbally.

There is adapted equipment that can be purchased which may help you increase your independence level with your bowel management program. Some of these include a digital bowel stimulator, a suppository inserter, and even tools that help you wipe yourself. Talk to your occupational therapist to help you identify equipment that can help you.

Learning how to take care of your bowels will be important for your social life and overall health.

BOWEL PROGRAM SUPPLIES

- ✓ *Gloves (non-latex)*
- ✓ *Suppository, if needed*
- ✓ *Wet wipes, toilet paper or wash cloths*
- ✓ *Lubricant, water soluble (do not use petroleum jelly or Vaseline)*
- ✓ *Receptacle for disposal of stool and used supplies*
- ✓ *Disposable underpads*
- ✓ *Raised toilet seat or commode chair*
- ✓ *Adaptive Equipment:*
 - *Digital bowel stimulator*
 - *Suppository inserter*

When to go to the doctor for bowel issues:

- No bowel movement for three or more days
- Hard stool that will not come out
- Nausea
- Vomiting
- Severe diarrhea
- Blood in stool
- Frequent bowel accidents
- Increased spasms

For more information, see the Reeve Foundation Bowel Management booklet www.ChristopherReeve.org/BowelToolkit

Skin

Before discharge, make sure you learn ways to prevent pressure injuries or ulcers (bed sores). Developing a pressure injury can greatly impact your quality of life. They increase your risk of infection and affect your mobility. Pressure injuries happen on bony areas of your body that have not had enough pressure relief. This could occur because you were not regularly turned in bed or you are not fitting correctly in your wheelchair. There can be many causes of pressure injuries, but the main culprits are lack of pressure protection and relief to that area.

You should know the following before going home:

- Locate areas that often get pressure injuries
- Learn about equipment needed to protect yourself from pressure injuries
- How often you should be turning in bed?
- Does your wheelchair fit you and protect from pressure?
- What might you do if you find a pressure injury?
- How to perform adequate weight shifts when in your wheelchair
- Check your skin, even the areas that are hard to see

When to go to the doctor for skin-related issues:

- Any wound that has broken skin
- Foul odor or smell
- Pus or drainage coming out of wound
- Redness and/or tenderness around the sore
- Skin around wound is warm or swollen
- Fever/temperature of 100.4 degrees or higher
- Increased spasms

*For more information, see the Reeve Foundation Skin Care booklet
www.ChristopherReeve.org/SkinCareToolkit*

Autonomic Dysreflexia (AD)

Autonomic dysreflexia is an abnormal response to pain or discomfort in your body, below your level of spinal cord injury, which triggers blood pressure to rise until the cause is found and fixed or treated. If the cause is not found and treated immediately, serious complications such as a seizure or stroke may occur. A blood pressure increase of 20 to 40 points above your baseline or a systolic (top) number is a sign of AD. It is important to know your baseline or average blood pressure. The level and extent of the spinal cord injury determines how susceptible you are to autonomic dysreflexia. Anyone with an injury at T6 or above is at risk of experiencing AD. People with a spinal cord injury level of T6-T10 may be at moderate risk and those below T10 are usually not at risk for AD.

Autonomic Dysreflexia can become an emergency situation if not identified and treated immediately. The charts that follow show the signs and symptoms as well as the common causes of AD.

SIGNS AND SYMPTOMS OF AUTONOMIC DYSREFLEXIA

- *Severe, pounding headache*
- *Rapidly rising blood pressure (20-40-point rise above your baseline for adults, 15-30-point increase for children and teens)*
- *Slow heart rate*
- *Sweating above the level of injury*
- *Goose bumps below the level of injury*
- *Blotching, redness, or flushing of the skin (chest, neck, face)*
- *Stuffy nose*
- *Blurred vision*
- *Feeling of anxiety or nervousness*
- *A blood pressure reading with a systolic (top) number above 150*

COMMON CAUSES OF AUTONOMIC DYSREFLEXIA

- *Full bladder (blocked catheter, full collection bag, need to perform catheterization)*
- *Other bladder issues (urinary tract infection UTI), kidney stones, bladder stones)*
- *Bowel constipation or hard stool*
- *Pressure sores or skin irritation*
- *Contact with hard surfaces or sharp objects*
- *Broken bones*
- *Ingrown toenails*
- *Clothes or shoes fitting too tight*
- *Genital stimulation during sexual activity*
- *Menstrual cramps, ovarian cysts, or IUDs*

AD TREATMENT ACTIONS

- ✓ *Sit straight up to decrease blood pressure*
- ✓ *Loosen any tight clothing*
- ✓ *Check blood pressure immediately (may need caregiver assistance)*
- ✓ *Check/empty bladder (empty urine bag, be sure catheter tubing is not kinked, and/or perform catheterization if needed)*
- ✓ *Do rectal check and remove any stool (if blood pressure increases, stop rectal check)*
- ✓ *Check your skin for sores, any irritation, pressure, tight clothing or ingrown toenails*
- ✓ *If you are engaged in sexual activity, stop the activity*
- ✓ *If the symptoms of AD are not resolved, call 911 immediately*
- ✓ *If you are having more episodes of AD than usual, see your medical provider to look for potential causes of AD*

For more information, see the Reeve Foundation AD wallet card and the Craig Hospital AD card



Respiratory

Before your spinal cord injury, you may not have put much thought into breathing. Since your injury, your ability to breathe and clear your lungs may have changed. While your lungs still work the same way they did before your spinal cord injury, the muscles that help you breathe do not work the same. Just like the muscles in your arms and legs, your respiratory muscles may also be affected due to where your spinal cord was injured. Respiratory infection is the number one reason patients with cervical spinal cord injuries return to the hospital after being discharged from rehabilitation. It is also the leading cause of death after people living with spinal cord injury are discharged home.

Ways to stay healthy:

- Wash your hands
- Get out of bed, sit up, change positions
- Turn frequently
- Deep breathing
- Exercise (actively, if you are able or passively, with assistance)
- Shift your weight in the wheelchair
- Avoid sick friends and family until they are healthy
- Clean equipment
- Take breathing treatments as they are scheduled
- Get flu and pneumonia vaccines
- Don't smoke or allow smoking around you

Some people will need extra support to keep their lungs healthy at home. These could include the use of a tracheostomy tube, mechanical ventilator, inhaled breathing treatments, supplemental oxygen, etc. You will need to make sure to have all of this set up before you go home. Talk to your provider and respiratory therapist about what your specific needs might be.

It is important to know that people can go home on a ventilator if they have trained family or caregivers that can be with them at all times. It is imperative to notify local EMS and utilities if mechanical ventilation is required in case of emergency or power outage.

RESPIRATORY CHECKLIST

- ✓ **Oxygen**
- ✓ **Oxygen supplies (i.e. nasal cannula)**
- ✓ **Mechanical ventilator supplies**
- ✓ **Tracheostomy supplies (always have a backup)**
- ✓ **Suction machine and supplies**
- ✓ **Nebulizer**
- ✓ **Respiratory treatment medication**
- ✓ **CPAP, BiPAP machine and supplies**
- ✓ **Pulse oximeter**

When to see the doctor for respiratory problems:

- Fever/temperature of 100.4 degrees or higher
- Shortness of breath or difficulty breathing
- Increased secretions/mucus in your lungs
- Coughing

Feeding

Proper nutrition is needed for good health. You may need help feeding yourself if you have a high level of quadriplegia. You may also need assistance from a caregiver if you have dysphagia (swallowing problems) which is common in certain types of paralysis (ALS, CP, SCI, MS, stroke). You should try to maintain excellent oral hygiene. People with severe swallowing problems may need a feeding tube. Caregivers will need training to feel comfortable managing tube feeding. You may develop swallowing problems as you age with spinal cord injury due to cord tethering. Please see a physician and speech-language pathologist for an evaluation if you start to have swallowing problems.

QUESTIONS TO CONSIDER

- ✓ *Are you at risk of choking and thus may need food cut up smaller, pureed, or liquefied?*
- ✓ *Do you need assistance in meal preparation and/or set up?*
- ✓ *Are you able to self-feed or do you need partial or total assistance for feeding?*
- ✓ *Does your caregiver understand your feeding needs and equipment?*
- ✓ *Will you have any dietary restrictions as identified by a nutritionist or speech therapist?*
- ✓ *Will you need special eating utensils or straws for drinking?*
- ✓ *Has your caregiver been trained on proper placement of food in the mouth so that the gag reflex is not triggered?*

Deep Vein Thrombosis (DVT)

Deep Vein Thrombosis is a blood clot which can lead to lack of blood flow to an extremity causing internal tissue damage, swelling, and skin breakdown. If you have diminished sensation and are unable to feel pain or heat, have another person check your skin for you. The clot can break loose and travel to the lungs causing a pulmonary embolism. Pulmonary embolisms can affect breathing and heart function. A blood clot that travels to the brain may cause stroke and/or death. If you have a spinal cord injury,

the risk for a blood clot starts immediately after injury and the risk lasts for life. You are at heightened risk for DVT anytime you are immobilized due to illness, post-surgical recovery, and paralysis. **DVT is a medical emergency and you must see your health care provider or go to an emergency room immediately.**

WHAT ARE THE SIGNS OF A BLOOD CLOT?

- ✓ *Leg or arm swelling (these are the most common sites for a DVT)*
- ✓ *Tenderness in the calf, thigh, groin or arm*
- ✓ *Skin that is warmer than the surrounding areas*
- ✓ *Redness or whitish discoloration over the affected area*
- ✓ *Pain*
- ✓ *Low-grade fever*
- ✓ *Increased or new symptoms of autonomic dysreflexia if the spinal cord injury is at the T6 level or above*

Please contact the Reeve Foundation for their free DVT wallet card for more info on DVT. www.ChristopherReeve.org/cards

HOME MODIFICATIONS



A wheelchair can take up a lot of space. The ability to move around in your home will depend on how accessible it is. Most people will need to make some modifications (changes) to their home. There are many things to think about when considering what and if modifications will need to be done on your home. Check with your

rehabilitation center to consult with a PT/OT as they can give you the specifics on what is needed to make modifications that are up to code. The following list gives you some examples of things to think about when considering home modifications.

HOME AREAS AND ITEMS THAT MAY NEED TO BE MODIFIED

- ✓ *What are the dimensions of your wheelchair?*
My wheelchair is _____ height by _____ width
- ✓ *Doorway widths*
- ✓ *Hallway widths*
- ✓ *Entranceways:*
 - *Is a ramp needed? Ramps should be one foot in length for every one inch of rise*
 - *If you live in an area with inclement weather, consider putting a main entry ramp in the garage (from garage to inner door).*
- ✓ *Bathroom:*
 - *Accessible toilet*
 - *Roll in shower*
 - *Proper drainage*
 - *Threshold overlays*
- ✓ *Carpet versus hard flooring*
- ✓ *Kitchen:*
 - *Counter heights*
 - *Cabinet accessibility*
 - *Stove, oven, microwave accessibility*
 - *Sink (water temperature controls)*
- ✓ *Table heights*
- ✓ *Low or no cost options include:*
 - *Moving bedroom to the first floor*
 - *To increase accessibility, remove doors from bathrooms, pantries, or other rooms and hang a privacy curtain from a tension rod*

BENEFITS AND FINANCIAL RESOURCES

Understanding your health care coverage and other possible financial benefits/options available to you is very important.

Health and Accident Insurance

Each insurance policy is different and acts as a contract between you and your insurer. It is important for you to understand your coverage. A source of assistance can be your

human resource department and/or your insurance broker. While you are in the hospital, the hospital case manager can help you navigate this system. Once home, you will need to know the name of your insurance case manager who can be accessed by calling the number on the back of your insurance card. Some businesses only allow employees to keep their insurance coverage for a pre-determined length of time. You need to be aware of this timeline. Depending on how you were injured, you may be covered under workers' compensation, auto insurance, crime victim assistance, credit card insurance, retirement programs, sports insurance, etc. It is important to look and consider all plans that you have and use their coverage for different items.



Check into medical waiver programs available in your community.

Social Security

You may be eligible for Social Security Disability Insurance (SSDI). Eligibility is based on the amount of time you have worked and paid into the Social Security system. There is a six-month waiting period for SSDI and checks always arrive one month later, so if you are eligible, the first check would come seven months after the injury. If you receive 24 consecutive Social Security checks, you are then automatically eligible to enroll in Medicare Disability. If you are on Medicaid, your Medicaid case manager can assist you with the Medicare Disability application process.

Supplemental Security Income (SSI) and Medicaid

Supplemental Security Income is a federal program that is based on need and provides financial support to individuals with limited financial assets. Eligibility is determined by household income per month, the amount of funds in your bank accounts, and any assets you may have (i.e. car, 401K, stocks and bonds, trust funds, etc.). Not everyone qualifies for Medicaid. If you qualify, Medicaid will help pay for certain medical and rehabilitation services. Medicaid coverage varies per state. If you do qualify, choose physicians and providers who accept Medicaid.

Medicare

Medicare Disability is an option for some people with severe long-term injuries. Medicare Disability is available for a person who is age 65 or over, or if he or she has lived with a severe disability for a certain period of time (generally two years). Applying for Medicare Disability can be a long process and should be started as soon as possible. You will need to work with physicians and therapists who accept Medicare Disability.

Medicaid Waiver Programs

Some states offer special waivers specifically for people with spinal cord injuries. These may help cover special services for people with a spinal cord injury.

Other financial options may include:

- Fundraising*
- Personal Savings
- Private Grants
- State Grants
- Special Needs Trust Fund

* *Check with your tax professional before fundraising so that you don't lose your benefits or incur tax penalties.*

T R A N S P O R T A T I O N

A spinal cord injury/paralysis does not mean that you will be restricted to your home. You will need to consider how to get around your community. Some people will use public transportation while others will purchase an accessible vehicle.

Your type and level of injury may determine the vehicle you can use. A power wheelchair user will most likely need to be transported in a vehicle that has a lift or a ramp. A person in a manual wheelchair can usually ride in a car because the manual chair can be folded to fit into the trunk of the car.

When using public transportation, you should receive training on how to get on and off a bus safely. You should also know how to secure your wheelchair independently or verbally walk someone through the steps. The lift used on buses can be intimidating but with practice, you'll learn how to use them safely and comfortably.

BEFORE YOU PURCHASE A VEHICLE CONSIDER...

- ✓ *Your age and overall health*
- ✓ *The size of your wheelchair*
- ✓ *Your ability to transfer independently*
- ✓ *Whether you'll be a passenger or driver*
- ✓ *Funding, including outside sources*

Do not purchase a vehicle before you have your primary wheelchair to make sure your wheelchair fits in the vehicle.

Emergency Preparedness and Planning

Planning for emergencies will help you manage them better if and when they occur. Everyone should have an emergency plan, but after paralysis, it is even more important.

Meet with your local/neighborhood police and fire departments: Make a trip to your local police and fire departments to introduce yourself to the first responders. Getting to know them on a personal level creates a stronger relationship and allows them to better meet your needs. Make sure your address is flagged on dispatch to assist the responders in better anticipating your needs.

Notify your local utility providers: It is important to let your utility providers know that a household member uses critical medical equipment (ventilator, power wheelchair, etc.) and may require air conditioning or heat due to an inability to regulate body temperature. This will ensure that in a power outage your home is given priority in recovering power. Your utility company may require a form to be completed and signed by your doctor.

Emergency contacts: Knowing who to contact in case of an emergency is important for you and those who need to take care of you. You should keep this list in a place that can be easily accessed. Examples of names and numbers your list should contain are:

- Family
- Fire department
- Police department
- Poison control
- Hospital
- Primary care physician
- Specialty physicians
- Insurance information
- Nurse advice lines

There are websites and apps for cell phones (search your app store using keyword: “emergency preparedness”, “Red Cross”, “FEMA”) that can assist you in creating and storing this information. Visit your city or county websites to find out if they have these systems already in place.



WHAT TO SHARE WITH FIRST RESPONDERS

- ✓ *The kind of injury you have along with other medical conditions*
- ✓ *Location of medications*
- ✓ *If there is oxygen in the house and where it is stored*
- ✓ *How much help you will need during an emergency*
- ✓ *The layout of your house, especially bedrooms (If there was an emergency or fire, they could focus on getting to you as quickly as possible)*
- ✓ *Location of main exits, and which are the easiest for you to get out of*
- ✓ *How many people live in the house*
- ✓ *Your emergency contacts*
- ✓ *Vehicle descriptions*
- ✓ *If there are any pets, service animals, livestock on the property*
- ✓ *How your wheelchair should be handled and transported*

Planning for Emergencies

Emergencies are not something we like to think will happen. They can be even more uncomfortable to talk about. However, it is important to sit down with your family and caregivers to create a plan in case of an emergency. Creating a list or document can help keep everyone organized. Your list can contain any information you find helpful.

EXAMPLE OF EMERGENCY CONTACTS OR VITAL INFORMATION:

- ✓ *The person/people you want contacted and their phone number(s)*
- ✓ *Make a family telephone tree*
- ✓ *Utilize social media and Red Cross app/website to post about your safety for family and friends*
- ✓ *The hospital to which you want to be taken*
- ✓ *Your primary physician's name and contact information*
- ✓ *Medication and allergies list*
- ✓ *Insurance information*
- ✓ *A meeting place in case of community or other disaster that forces you from your home*
- ✓ *Who will assist with skin, bowel, and bladder management*

Groceries

If you are not able to easily get out into the community, there may be other options for getting groceries and meals in your area. Options in your area may be:

- Grocery stores and online retailers that offer ordering, meal subscriptions, and delivery
- Organizations that prepare and/or deliver meals to people that have the need (i.e. Meals on Wheels)
- Friends and family
- Local food banks
- Community centers or nonprofit organizations that provide meals or meal delivery

Ask family, friends, and neighbors to help you

It may not be as easy to get out and do the everyday things you need to do. Therefore, you may need help from your family, friends, or other people in your community. Often people close to you will offer to help but may not be sure how. When people offer to help, it is important to give them a specific task.

"You have to be vulnerable, not afraid to ask for help."

- Erin Husman

Sometimes creating a to-do list can help you identify certain needs. Ways people may be able to help are:

- Grocery shopping
- Laundry
- Lawn care/snow removal
- Trash removal
- Pet care
- Car servicing
- Dry cleaning
- Errands
- Transportation to appointments
- Equipment assembly
- Cleaning
- Childcare
- Getting the mail from the mailbox and taking mail to the post office



GETTING ORGANIZED

Returning home means the reality of having to be responsible for the tasks you had before. One of these is paying your bills.

Medical bills can be confusing and overwhelming. Before you make any payments on your medical bills, wait to receive your final explanation of benefits (EOB). Be aware of what your insurance company has paid so far. Keep all bills and receipts in a file for easy reference. Keep track of your medical expenses to know when you have reached your maximum individual/family deductible. You can track this via your insurance online platforms to avoid overpaying medical copays.

Household bills will still need to be paid. It is important to organize and set up a system to avoid missing payments. You may want to have a family member or friend assist with this responsibility. Take advantage of online banking and bill pay.

YOUR SOCIAL SELF

There are still many opportunities for socializing and having fun. For some people, it is harder to imagine how this is going to happen. Think about what you did before. Almost every activity has an adapted version. With a little research, you can find many resources! Places to think about when getting back to your social life are:

- What is going on in your community? Some communities put on festivals, parades, dinners, craft fairs, etc. These are good opportunities for getting out of the house and visiting with others.
- Independent living centers offer daily programs and activities
- Faith-based communities
- Find an adapted sport or recreation center in your area
- Local support groups and rehabilitation centers are good resources



KNOW YOUR RIGHTS

The Americans with Disabilities Act (ADA) has positively changed access and treatment of people with disabilities. There are many rules and regulations that ensure equal treatment of all people. There are regional ADA assistance centers that can provide resource and guidelines. Not everything is covered by the ADA. There may be other regulatory agencies or guidelines (i.e. Air Carriers Access Act) or state regulation that pertain to the rights of people with disabilities. Some communities have hotlines for reporting non-accessible buildings or violations of rights.

Remember to know your rights; this will help you navigate through life. You will need to be your own advocate and speak up for yourself.

EMPLOYMENT AND EDUCATION

Many people living with paralysis may return to work or school after their injury. There are laws put in place to protect people when they have a medical issue that requires them to miss work for an extended period of time such as the Family and Medical Leave Act (FMLA). FMLA provides coverage for caregivers and people with disabilities. Not all employers are mandated to offer FMLA, so check with your employer.

Many teens and young adults return to college after a spinal cord injury. You may need specific accommodations. It is important to work with the school and get your needs addressed before starting classes.

Vocational Rehabilitation (VR)

Every state has a federally funded agency that administers vocational rehabilitation, supported employment, and independent living services. VR assists people in finding jobs through local searches and by promoting self-employment and telecommuting opportunities. VR services vary widely depending upon the state but typically include medical, psychological and vocational assessments; counseling and guidance; vocational and other types of training; interpreter and reader services; services to family members; rehabilitation technology; placement; post-employment services; and/or other goods and services necessary to achieve rehabilitation objectives. In some cases, VR pays for transportation and vehicle modification.

TECHNOLOGY

In today's fast-paced world, almost everyone uses technology in their daily life and to stay connected with others. The same is true for people with a spinal cord injury. Assistive Technology (AT) is any item, piece of equipment, software program, or product system that is used to increase, maintain, or improve the functional capabilities of persons with disabilities. Assistive Technology is used to compensate for physical, cognitive, language, and visual impairments, enabling patients to reconnect to their daily life.

By knowing more about the latest software and technology options on the market, people can be safer, require less attendant care, return to work or school sooner and enjoy a higher quality of life.

Examples of adaptive equipment include:

- Voice activation systems
- Mouse devices
- Microphones
- Keyboards
- Mounts, holders, and stands
- Bluetooth ear pieces
- Various ways of controlling their environment (such as their television, lights and doors)
- Smart and talking devices
- Alternative communication devices
- Call systems
- Software programs

In Conclusion...

By becoming educated and organizing new support systems, discharging from a hospital or rehabilitation facility will be less stressful. This booklet covers some ideas on how to be healthy and successful outside of the hospital. Take time to work with your case manager or discharge planner to get things in place before going home. You've made great strides in the rehabilitation setting, now it's your chance to practice what you have learned.

My accident happened before the Internet was a resource. When I was leaving the hospital, my family and I relied on networking with peers and resources in our community. It really helps to put yourself out there!" - Rachel Wilson

T A S K	T I M E L I N E <i>Based on length of rehab stay which varies by individual*</i>	N O T E S
Find a Primary Care Physician (PCP) who can accommodate your new needs or make sure your current one can	Start upon admission into rehab	
Educate your caregiver on your various needs	Starts upon arrival, ongoing throughout rehab	
Learn what assistive technology needs you have; determine how to try out AT devices before buying	Start assessment of needs immediately upon arrival in rehab	
Learn feeding routine	Starts upon admission, ongoing until discharge	
Check insurance policies for coverage terms to determine any benefits	Immediately after admission to rehab, ongoing as needed	
Review and use short and long-term disability; Apply for SSI/SSDI	Immediately after admission to rehab contact Human Resources about disability if you are employed. Apply for SSI/SSDI once on long term disability	
Determine if you are eligible for Medicaid waiver program	Immediately after admission to rehab	
Make any immediate or critical home modifications needed to return home	Begin assessment shortly after admission to rehab. Start implementing changes one month prior to discharge	
Learn what Durable Medical Equipment needs you have; determine how to pay for them	OT and PT can help start determining needs soon after arrival	
Put a plan in place to continue your education if you were a student; learn what accommodations your school will give you	Soon after arrival at rehab, the school district (K-12) will send someone to help you continue your education while you are in rehab.	
Learn bladder management	Hospital will teach within 1-2 weeks of injury, master by discharge	
Learn bowel management	Hospital will teach within 1-2 weeks of injury, master by discharge	
Learn skin care management	Hospital will teach within 1-2 weeks of injury, master by discharge	

T A S K			T I M E L I N E			N O T E S		
<i>Based on length of rehab stay which varies by individual*</i>								
Learn the signs of autonomic dysreflexia			Hospital will teach within 1-2 weeks of injury, master one week prior to discharge					
Learn the signs of DVT/blood clots			Hospital will teach within 1-2 weeks of injury, master one week prior to discharge					
Educate yourself about disability rights and laws; prepare to self-advocate			One month prior to discharge then on-going					
Set up appointments with specialists			One month prior to discharge so that you have appointments within one month of discharge					
Plan how you will prepare and/or receive meals			One month prior to discharge					
Review your employment options; can you return to your previous job or do you need vocational rehabilitation?			One month prior to discharge					
Make a list and order bladder and bowel management supplies			Make list one month prior to discharge, order one week prior to discharge					
Home Care vs Long Term Care decision based on how much care you need post-discharge			One month prior to discharge					
Prepare for any assistance you need with paying bills and running your household			One month prior to discharge					
Educate yourself on what type of accessible vehicle or transportation you need			Explore one month before discharge but hold off on purchase until you have purchased your primary wheelchair					
Set up personal care supplies needed at home			Prepare list two weeks prior to discharge					
Prepare an emergency plan that can be instituted upon return home			Two weeks prior to discharge					
Create list of medications and allergies			One week prior to discharge					
Obtain needed prescriptions			2-3 days before discharge					
Think about social opportunities you can participate in after discharge			Once home					

***Note:** This chart is intended for use as a guideline. It offers items for you to think about so you are prepared as you transition home. Actual times will vary with length of stay, level of injury, and your specific needs.





WE'RE HERE TO HELP.

Learn more today!

Christopher & Dana Reeve Foundation

636 Morris Turnpike, Suite 3A
Short Hills, NJ 07078
(800) 539-7309 toll free
(973) 379-2690 phone
ChristopherReeve.org

Craig Hospital

3425 S. Clarkson Street
Englewood, CO 80113
(800) 247-0257
(Nurse Advice Line)
CraigHospital.org

This project was supported, in part, by grant number 90PRRC0002, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.