



Shepherd Center

# rebuilding, together

a guide for caregivers

*courtesy of shepherd center*

You will likely get a lot of information about spinal cord injury in the coming days. Caregivers, well-meaning friends, the Internet, spinal cord injury support groups, and families of other patients are all good sources of information, but it's a lot to take in. Don't try to learn everything at one time. Rely on your loved one's professional caregivers to let you know what you need to be concerned about next. *You've come to the right place, and your loved one is in the hands of experienced caregivers.*

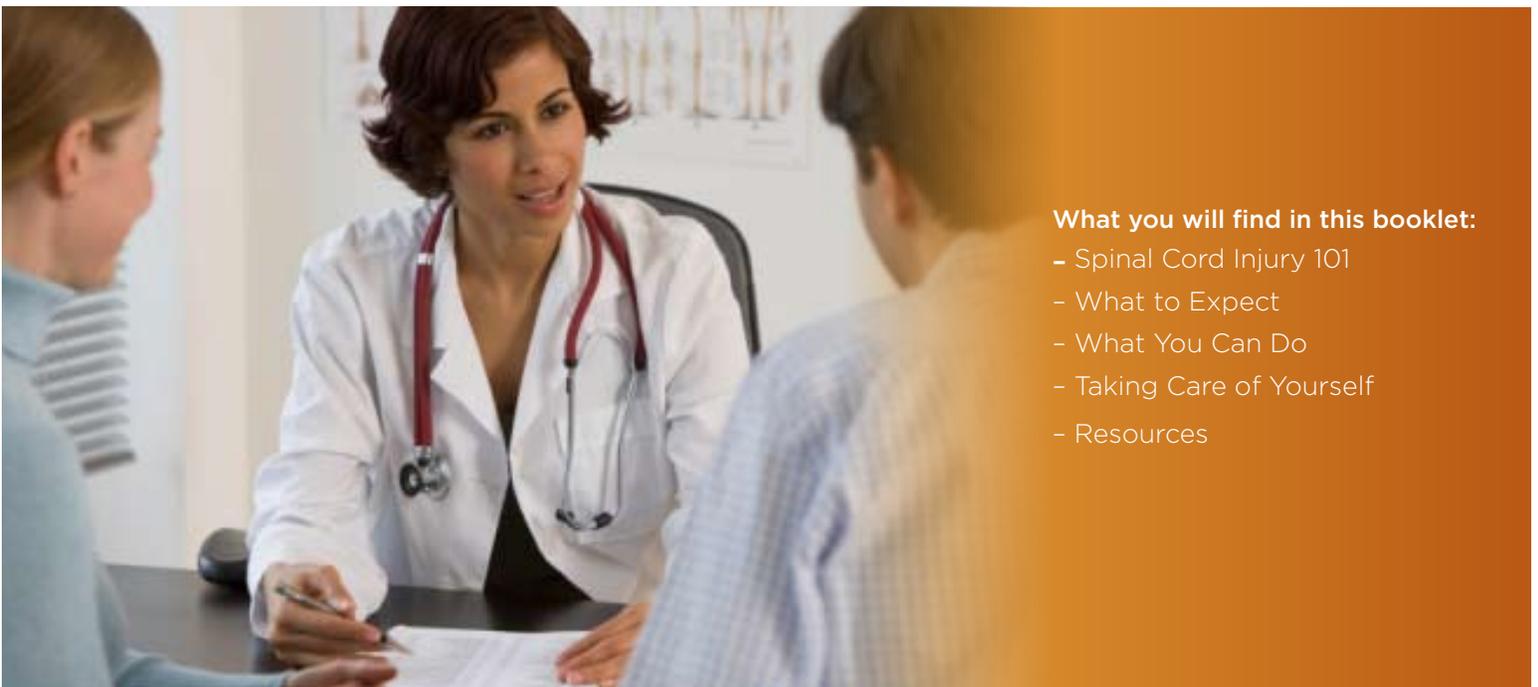
**The first few hours, days and weeks following a spinal cord injury are a scary and difficult time for a patient's loved ones. Getting over the shock of the initial injury and learning everything you need to know about what will come next can sometimes be overwhelming.**

Recovery from spinal cord injury is unpredictable, and that can be very frustrating. The medical world is sometimes fast-paced, and care happens around the clock. There is a whole new language to learn. Answers may seem hard to come by right now. Understanding all of this and what it means for your loved one will come in time. Right now, you need to do what you can to cope and to take care of yourself, hour by hour and then day by day.

In the pages of this booklet, you'll find information and advice that will help you through these first weeks. You'll also find comments from families of patients who have traveled this road before you.

***But more than anything else, they want you to know it's going to be OK.***

Whatever level of recovery your loved one makes, you are surrounded by a team of knowledgeable and caring professionals who will help you make the changes you'll need to make to return to a more normal daily routine.



**What you will find in this booklet:**

- Spinal Cord Injury 101
- What to Expect
- What You Can Do
- Taking Care of Yourself
- Resources

## *spinal cord injury 101*

The most important — and sometimes frustrating — thing to know is that every person's recovery from spinal cord injury is different. Doctors will make educated predictions based on the location, type and extent of injury, but in the end, each person's recovery will be unique. Spinal cord injury can affect a person physically, as well as emotionally.

### SOME PROBLEMS WE WILL LOOK FOR INCLUDE:

- Physical
- Loss of sensation (feeling)
- Loss of movement
- Changes in bowel and bladder control
- Inability to cough
- Inability to breathe properly
- Changes in blood pressure and circulation
- Changes in skin integrity
- Emotional
- Denial
- Depression
- Anxiety
- Grief
- Anger

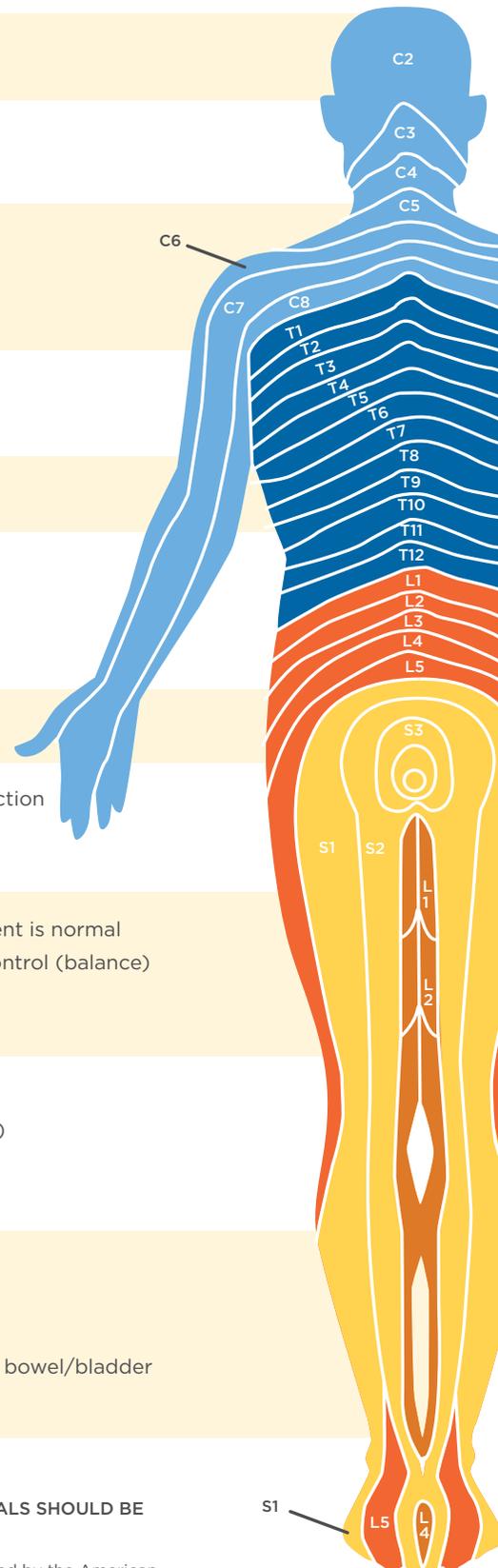


### SOME INFORMATION ABOUT THE SPINAL CORD

- Your neck and backbones (also called vertebrae) surround and protect your spinal cord. The main job of your spinal cord is to be the communication system between your brain and your body. You can break your neck or back bones and not hurt your spinal cord. If the spinal cord is damaged, you can lose neural messages about feeling and movement from the damaged point and below. The chart on the next page will show you the relationship between nerves and muscles.
- Damage to the spinal cord can happen in many ways. It can be from loss of blood to the cord from a tumor, a stenosis (narrowing of the bony area where the cord sits) or even a stroke on the cord. Or the damage can be from a motor vehicle collision or a fall where the vertebra is broken, and that can crush, penetrate or pinch the spinal cord.
- The recovery takes place when the bony problems are fixed in surgery (if needed) and the swelling on the cord starts to go down. Sometimes after the swelling goes down, you may get more feeling or movement in your body. Remember that it is almost impossible to determine who will have return of feeling or movement.

# spinal cord injury functional chart

| Spinal Cord Level/<br>Spinal Nerve | Spinal nerve<br>connected to muscle   | What can the<br>muscles do?  |
|------------------------------------|---|--|
| <b>C1 to C3</b>                    | <ol style="list-style-type: none"> <li>1. Neck (sternocleido-mastoid)</li> <li>2. Shoulder (trapezius)</li> </ol>                                 | <ol style="list-style-type: none"> <li>1. Lift head</li> <li>2. Shrug shoulders</li> </ol>   |
| <b>C4</b>                          | <ol style="list-style-type: none"> <li>1. Diaphragm</li> <li>2. Neck (sternocleido-mastoid)</li> <li>3. Shoulder (trapezius)</li> </ol>           | <ol style="list-style-type: none"> <li>1. Breathe</li> <li>2. Lift head</li> <li>3. Shrug shoulders</li> </ol>   |
| <b>C5</b>                          | <ol style="list-style-type: none"> <li>1. Shoulder (deltoid)</li> <li>2. Arm (biceps)</li> </ol>  | <ol style="list-style-type: none"> <li>1. Raise arms</li> <li>2. Bend elbows</li> </ol>  |
| <b>C6</b>                          | <ol style="list-style-type: none"> <li>1. Wrist extension</li> </ol>  | <ol style="list-style-type: none"> <li>1. Bend wrist up</li> </ol>   |
| <b>C7</b>                          | <ol style="list-style-type: none"> <li>1. Elbow extension</li> <li>2. Some finger extension</li> </ol>  | <ol style="list-style-type: none"> <li>1. Straighten arm at elbow</li> <li>2. Normal movement or shoulder muscles</li> </ol>                                       |
| <b>C8</b>                          | <ol style="list-style-type: none"> <li>1. Finger flexors</li> </ol>   | <ol style="list-style-type: none"> <li>1. Can grasp objects</li> </ol>   |
| <b>T1 to T5</b>                    | <ol style="list-style-type: none"> <li>1. All hand muscles</li> <li>2. Upper chest and more back muscles</li> </ol>                               | <ol style="list-style-type: none"> <li>1. All arm and hand function is normal</li> </ol>   |
| <b>T6 to T12</b>                   | <ol style="list-style-type: none"> <li>1. All chest</li> <li>2. Trunk muscles (depending on level)</li> <li>3. Abdominal muscles</li> </ol>       | <ol style="list-style-type: none"> <li>1. Upper body movement is normal</li> <li>2. Fair to good trunk control (balance)</li> <li>3. Cough productivity</li> </ol> |
| <b>L1 to L5</b>                    | <ol style="list-style-type: none"> <li>1. All lower back</li> <li>2. Some leg (quadriceps)</li> </ol>   | <ol style="list-style-type: none"> <li>1. Bend hips (L2)</li> <li>2. Straighten knees (L3)</li> <li>3. Pull ankle up (L4)</li> <li>4. Extend toe (L5)</li> </ol>   |
| <b>S1 to S5</b>                    | <ol style="list-style-type: none"> <li>1. Ankle</li> <li>2. Knee</li> <li>3. Hip</li> <li>4. Bowel control</li> <li>5. Bladder control</li> </ol> | <ol style="list-style-type: none"> <li>1. Push foot down</li> <li>2. Bend knee</li> <li>3. Extend hip</li> <li>4. May begin to control bowel/bladder</li> </ol>    |



USE THIS CHART AS A GENERAL GUIDELINE, KEEPING IN MIND THAT EVERYONE IS UNIQUE. GOALS SHOULD BE BASED ON THE PERSON'S ABILITIES AND RECOVERY.

Source: The American Spinal Injury Association (ASIA), International Medical Society of Paraplegia. Supported by the American Paraplegia Association.

## *what to expect*

Your loved one is most likely in the Intensive Care Unit (ICU) of your local hospital, where the nurses and doctors can constantly monitor his or her condition. Entry into the ICU provides the first steps in the recovery process. The first view you have of your loved one may be upsetting.



“It’s been a challenge for the rest of my family, especially my youngest daughter – she really misses her mom. My husband has had to pick up all the pieces and the jobs I used to do. Your family just has to pull together to deal with all the circumstances.”

— Linda Lindquist, mother of a 19-year-old girl who sustained a paralyzing spinal cord injury in a snow skiing accident

- Don’t be alarmed by the number of tubes and wires you see hooked up to your loved one’s body. They all serve a purpose in delivering medication or monitoring the body functions so the medical staff can be aware of the slightest change.
- You may see cuts, swelling or bruising, depending on the nature of the injury. This will heal.
- Before surgery, doctors may place your loved one in a traction device. This is to keep the spine aligned prior to surgery.
- Your family member may or may not be able to feel you touching them. It is OK to touch them or hold their hands, even though they may not feel it; it is comforting to know you are there. You may need to inform them that you are touching them.
- Visiting hours in the ICU are limited. The nurses will tell you when you can visit.
- The goal of the ICU stay is to medically stabilize your loved one.
- Once stabilized, your loved one will be transferred to a hospital room.

## *what you can do*

Always check with your loved one's caregivers before initiating any activity. The location of their injury on the spinal cord will affect how much they can do for themselves.

Be involved with the caregiving to your family member. If you are not comfortable doing hands-on activities with your loved one, have the caregiver explain the care they are providing. These activities may include bathing, grooming, feeding, and range of motion or skin checks. The more you are involved with their care, the easier your transition to rehabilitation and home will be.

- Don't overdo it. Allow time to rest between your visits.
- Limit the number of visitors at one time and maintain a calm tone of voice.
- Encourage deep breathing and coughing.
- Assume he or she can hear you. Be careful not to say anything upsetting within earshot.
- Encourage your loved one to get out of bed and sit up if he or she is able to do so.



## *what to expect in the rehab setting*

As your loved one's health status improves, the doctor may recommend transferring into a rehabilitation program. Typically, the main goals of rehabilitation are to increase a person's strength, learn new ways to do things after an injury and help them return to their lives and community. Not only is this a time for your loved one to learn, but it's a time for you to learn how to help them.



### WHAT YOU SHOULD BRING TO REHABILITATION FOR YOUR LOVED ONE:

- Loose comfortable clothing such as:
  - sweat pants
  - T-shirts
- Socks
- Underwear (consider boxers)
- Shoes (buy shoes at least one size larger and make sure they have a rubber sole)
- Toiletry items such as a
  - toothbrush
  - toothpaste
  - comb
  - brush
  - shampoo
  - soap
  - deodorant
- Familiar items such as
  - photos
- Comfort items, such as a favorite
  - pillow
  - blanket
  - music
- Leave valuable items at home

## *what you can do*

This journey is a long one, and there will be many detours along the way. Once the first few hours or days have passed, you must take breaks from the hospital to sustain yourself for the coming weeks and months. You also need to find a system that works for you in terms of how you organize the questions you have, the information you need to receive and the people to whom you talk.

### **BEING A CAREGIVER IS NOT SOMETHING YOU MAY BE AUTOMATICALLY PREPARED TO DO, BUT THESE IDEAS WILL HELP:**

#### **BUY SEVERAL SMALL NOTEBOOKS**

Use one for phone numbers, one for doctor/treatment team information and questions, and one for information about insurance and other financial matters.

#### **CHOOSE A SPOKESPERSON**

Family members and friends will want information, and it is exhausting to repeat the daily updates. You can appoint someone to keep notes and provide updates via phone or the Internet to update concerned family and friends.

#### **STAY IN TOUCH WITH YOUR CASE MANAGER**

Your case manager will assist you along the way with discharge plans.

#### **USE THIS TIME TO LEARN ABOUT SPINAL CORD INJURY**

But take it slow. There is a lot of information, and it can be overwhelming. The library staff at the hospital, the chaplain and your loved one's case manager, as well as other team members, can help supplement the information you receive from the doctors.

#### **START A JOURNAL**

This would be especially good if it seems like something that would help you deal with your grief. Reading it might be helpful to your loved one as he/she recovers.

#### **TALK TO OTHER PATIENTS**

Encourage your loved one to talk to other people who are recovering from a similar injury or illness.

## *taking care of yourself*

Taking care of yourself may seem time-consuming or even selfish, but your loved one needs you to be rested, well fed, alert and energetic so you are up to the task of caregiver.

### HERE ARE SOME THINGS YOU SHOULD DO FOR YOURSELF:

- Save your energy by resting when you can.
- Eat healthy meals; skip the vending machines.
- Exercise a little each day; go for a walk and stretch your muscles.
- Leave the hospital for a little while. Your loved one is in good hands.
- If you are experiencing any medical problems, such as heart palpitations, muscle aches and pains, headaches or difficulty thinking, sleeping, remembering things or making decisions, call your doctor.
- Keep life as normal as possible for your children if you have them, and try to do something special with them once a week.
- Ask friends and family to write short notes instead of calling. That way you'll have something to read to your loved one.
- Talk about your feelings with family, friends or someone at the hospital (a psychologist, counselor, case manager, chaplain or other staff members can help you).
- Accept offers of help from family and friends; it gives them a way to be a part of the recovery. You might keep a list of things that need to be done (caring for pets and houseplants, picking up the mail, scheduling activities for children, etc.) so that you'll be prepared when someone asks.
- Allow yourself to put off "until tomorrow" what doesn't have to be done in one day, but do try to take care of some personal business every day.

*“When someone goes through such a catastrophic injury and situation, I think it’s important that they work through that. It’s OK to cry and to be sad, and even go through some anger, but at the end of the day, the future is still the future, and it can be bright or it can’t be. I think a lot of it is about our mindset. I would encourage anybody to have a positive mindset and to know that life is not over, it’s just changed.”*

— Kenny Pope, 39, who sustained a paralyzing spinal cord injury after falling from his roof

## *resources*

The Noble Resource Learning Center at Shepherd Center is a library with information especially for family members and friends of people with spinal cord injury. The knowledgeable staff can help you locate the right resources. The library also has computers with Internet access.

**Spinal Cord Injury  
Information Network  
UAB Dept of Physical  
Medicine & Rehabilitation  
Spain Rehabilitation Center**  
1717 6th Avenue S  
Birmingham, AL 35233-7330  
205-934-3450  
[www.spinalcord.uab.edu](http://www.spinalcord.uab.edu)

**Christopher & Dana Reeve  
Paralysis Resource Center**  
636 Morris Turnpike  
Suite 3A  
Short Hills, NJ 07078  
800-539-7309  
[www.paralysis.org](http://www.paralysis.org)

**American Spinal  
Injury Association**  
2020 Peachtree Road, NW  
Atlanta, GA 30309-1402  
404-355-9772  
[www.asia-spinalinjury.org](http://www.asia-spinalinjury.org)

**National Spinal Cord Injury  
Association**  
6701 Democracy Blvd.  
Suite 300-9  
Bethesda, MD 20817  
800-962-9629  
[www.spinalcord.org](http://www.spinalcord.org)

**Paralyzed Veterans of America**  
801 Eighteenth Street, NW  
Washington, D.C. 20006  
800-424-8200  
[www.pva.org](http://www.pva.org)

**Brain and Spinal Cord Injury  
Trust Fund**  
2 Peachtree Street NW  
Suite 8-212  
Atlanta, GA 30303  
404-651-5112  
[www.bsitf.state.ga.us](http://www.bsitf.state.ga.us)



*Visit us online at [shepherd.org](http://shepherd.org)*

*The Billi Marcus Building*

*The Jane Woodruff Pavilion*

**SHEPHERD  
CENTER**





## Shepherd Center

2020 Peachtree Road, NW  
Atlanta, GA 30309-1465  
404-352-2020 [shepherd.org](http://shepherd.org)