PREPARING FOR AN EXTENDED HOSPITAL STAY

Every year, about 12,500 people survive spinal cord injuries.

Given the catastrophic nature of these injuries, the simple act of survival can feel like a miracle, and certainly an incredible feat. As you and your loved one prepare for the realities of recovery—which typically include multiple surgeries, lots of bureaucratic red tape, a long hospital stay, and an even longer recovery and rehabilitation period—you may begin feeling overwhelmed.

The first and most important thing to know is that it is normal to feel stressed. Of course you’re glad your loved one survived, but frustration, anxiety, and even a little resentment are all normal. You didn’t think this was how you’d be spending your time, and we all struggle when our expectations aren’t met. You should anticipate a range of emotions, and should allow yourself to freely and fully feel them all.

Organizing your life, learning about traumatic injuries, and having the things you love the most can all help you regain a sense of control. When your loved one’s life has suddenly and dramatically changed, that sense of control can help you push through even when life feels completely unmanageable.

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DEAL WITH IMMEDIATE NEEDS FIRST

Trauma does strange things to the brain. The tasks that might seem obvious can take a backseat to what’s right in front of you. So step back, take a deep breath, and take these first steps before you do anything else:

- **Gather you and your loved one’s cell phone and charger.**
- **Tell your children and family about what has happened.**
- **Contact your employer and your loved one’s employer to let them know you will need time off.**
- **Ask someone to go by your house to watch your pets.**
- **Get some sleep.** Everything feels worse when you are sleep-deprived, and staying awake night after night will do your loved one no good.
CONTACT YOUR INSURER

After you have dealt with the immediate aftermath of the injury, it’s time to face the music. You will need to call your insurer to determine which care is covered so you can begin budgeting—and, if necessary, seeking help from loved ones or pursuing a loan. Most hospitals have financial counselors on staff, and many will negotiate with the insurer on your behalf.

Don’t hesitate to ask for help if you need it.

And remember, specific laws govern what insurers can and cannot do, so if you feel like you’re being taken advantage of, talk to a lawyer who specializes in health law.
CREATE A HOSPITAL CARE PACKAGE—FOR YOU AND YOUR LOVED ONE

Staying in the hospital should not mean chronic boredom. Indeed, if your injured loved one spends all of his or her time bored, it may be harder to recover, since depression and anxiety will be more likely. You both need and deserve comfort, so pack a bag for each of you containing items that keep you comfortable, happy, and feeling loved.

Don’t forget about:

+ A favorite stuffed animal or other meaningful object; this can be especially helpful if your loved one misses home.
+ A few extra blankets if the hospital room is too cold.
+ Sheets from home; they’ll be way more comfortable than what you get at the hospital. Bring a couple of pillows, too.
+ Headphones & an MP3 player.
+ A few beloved books.
+ Extra smartphone chargers.
+ A favorite project, such as knitting or a craft project.
+ Plush, anti-slip socks
+ Earplugs so you can sleep better.
+ Essential toiletries, including make-up, shampoo, and a favorite lotion.
+ A reading light.
+ Pen and paper.
+ 2-3 changes of clothes.
+ Comfortable sleeping attire.
+ A tray. This makes it easier to transport your loved one’s items.
+ An eye mask, and a diary or journal.
+ A laptop, tablet, or other device on which to watch movies and television. If the hospital TV has a DVD player, bring some DVDs, too.
Hospitals can feel cold and anything but homey. But there’s no rule that says they have to stay that way.

Indeed, feeling comfortable can actually improve your loved one’s recovery by boosting his or her morale.

DO WHATEVER YOU CAN TO HELP THE HOSPITAL ROOM FEEL MORE COMFORTABLE

- Bring some photos from home to display, or keep the door closed for privacy.
- Ask medical providers to softly knock before entering, since this improves privacy.
- If the hospital allows it, you might even put up curtains.
PRACTICE GOOD SELF-CARE

When you’re worried about a loved one, it’s easy to forget to care for yourself. But you cannot help your loved one if you’re in poor health or struggling with overwhelming emotions. Good self-care is vital to your loved one’s recovery journey; do not martyr yourself by sacrificing your own health!

ON A DAILY BASIS, TRY DO EACH OF THE FOLLOWING

Shower, dress, and engage in your usual getting ready ritual.

Talk to someone you love—ideally about something other than the injury.

Do something you enjoy, even if it’s just for 10 minutes.

Take some time to yourself. You do not have to be with your loved one 24/7, and you deserve a few moments to relax.

Eat healthy, balanced meals. Fiber and protein are especially vital for good mental and physical health.

Get moving. Aim for at least 30 minutes of aerobic exercise, such as walking or swimming, each day.

Get at least eight hours of sleep. If you can’t sleep you can’t think. And if you can’t think, then you cannot be an effective advocate for your loved one.

Meditate or pray. Research shows that sustained periods of mindfulness can improve both mental and physical health.
When something catastrophic happens, it’s tempting to give up on any semblance of normalcy. After all, life as you know it might have changed forever. But routines are comforting, and they’re often key to preventing the rest of life from falling apart.

Don’t pull your kids out of school or abandon your book club. Allow those routines to continue to give shape to your life. They also help remind you that life goes on, even when life is unbearably difficult. Better still, consider developing a clear schedule, then sticking to it each day.

Your schedule can provide massive reassurance when you’re overwhelmed, and it gives you a sense of control in the midst of a situation that might otherwise leave you feeling out of control and helpless.
Like it or not, you’ve been initiated into an entirely new world, with its own set of expectations, coded terms, and jargon. What was once normal might not be again, and that which seems strange could actually be quite common in the world of spinal cord injuries.

What you see in movies and on television—brave injury survivors recovering rapidly thanks to will, grit, and a little love—is rarely the reality. The world of spinal cord injury survivors is more complicated than any story can reduce it to.

Talk to your loved one’s doctor to get a clear picture of the recovery journey you can expect. Generally speaking, the following is normal:

- A range of emotions, including depression. Your loved one may be inconsolable, and even suicidal, for a time.
- Changes in your loved one’s personality.
- Difficulty with rehabilitation and physical therapy; your loved one might avoid treatment for anywhere from a few days to weeks. Remember, physical therapy is challenging, and often painful.
- A range of reactions from loved ones.
- Changes in the way people treat your loved one. Even when only his or her movement is compromised, you can expect that people may treat him or her like a “disabled person.” Knowing your rights, advocating on behalf of your loved one, and encouraging others to treat your loved one with dignity can all help.
- Conflict with doctors. When you’re dealing with a complex medical condition, it’s normal to occasionally disagree with your doctor.
KNOW WHAT’S NORMAL—AND WHAT’S NOT

THE FOLLOWING ISSUES, THOUGH COMMON, WARRANT OUTSIDE HELP:

+ Prolonged thoughts of suicide, either by you or your injured loved one.
+ Doctors who refuse to listen to you or your wishes.
+ Outright discrimination by any entity, but especially employers.
+ Insurance refusing to cover any care at all, or calling it a pre-existing condition.
+ Injury liability from an outside party.
Like the child who worries about the monster under her bed, or the woman who does not know when or if her spouse is ever coming home, we tend to panic when we don’t know what to expect. Spend some time educating yourself about spinal cord injuries. You might find information you don’t like, but knowing what to expect allows you to craft a realistic plan informed by the facts, not by fear.

The Internet allows anyone to post anything and present it as fact.

Choose your sources carefully, and steer clear of alarmist sites and those that are far outside of the mainstream.

There’s one exception to this rule: though message boards are often populated with horror stories and inaccurate information, they’re a great way to gain support and insight.

SpinalCord.com aims to help you in your journey to gather spinal cord information. For additional resources, these sites routinely offer reliable advice and information:

- National Spinal Cord Injury Statistical Center
- U.S. National Library of Medicine
- Mayo Clinic
- Shepherd Spinal Center
- United Spinal Association
- Model Systems Knowledge Translation Center
- Christopher and Dana Reeve Foundation

The journey to recovery is rarely short and never easy, but your life will get better. The way you feel today is not how you will feel even a day from now, let alone a week, month, or year down the road. If you need help, don’t be afraid to seek mental health assistance; many spinal cord injury survivors find that a therapist is invaluable on the road to recovery. And if you’re overwhelmed by financial and legal issues, talk to an attorney, who can help you begin sorting through your options.