



CHAPTER THREE

Acute Care





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As frightening as it is to be newly injured, acute care is a powerful step forward on the recovery journey, where experts can answer your questions and address some of your fears.

- Anthony Viao, SCIO Community Member



ACUTE CARE — DAYS, WEEKS AND MONTHS IN SURVIVAL MODE

You are now the most important person in your life.

As you start to figure out your new body, you have to look out for what is best for you. You are priority number one. Now your job is to ask questions. Lots of questions. Get a pen and a notebook, a voice memo on your phone, or any system that works for you to keep track of everything.

If you are not able to write or record notes, have someone do it for you. Ask your partner, friends, parents or someone else close to you to write everything down. Ask the nurses/PSWs to do it every time something happens or changes. Names of specialists, doctors, medications, timing of events, test results, what was said at appointments, recommendations of therapists ... you will thank yourself later for noting it all down! You will need to refer back to medications that you were treated with or remember which nurse helped you out with a particular problem. When you talk to peers, you will learn things that you may not know you needed to know!

Don't try this alone

Reach out to those around you. When you have run out of people to talk to, consult some of the resources listed at the back of this book. With the help of Spinal Cord Injury Ontario, we have put together a list of reliable websites to help you get through. Because you will get through — *it gets better*.

Intensive and Acute Care

This section has a series of interviews from trauma care providers. (There are a number of ways to sustain an SCI and not all require trauma or intensive care. Here we focus on those that do.) The overall message is to focus on healing, listen to what they say and know that they do have your best interests in mind. Most of all, ask questions. For a start, ask about the medications they give you, why they put you in different body positions, and how your bowels and bladder are functioning. Everything they do for you has a reason — ask why.

But first of all, who are all these people?

Your room will have a revolving door for the first while. You will see a lot of different nursing staff (RNs and RPNs) and PSWs (Personal Support Worker)

who support their work. Nurses will provide medication, monitor your urine output and check your wounds and your vitals. They will help with your bowel care (which is likely no longer in your control). PSWs will help you with your meals (if you need it) and help with your personal care (bathing and hair washing). Shift changes mean you will see many faces, some possibly only once!

You will also see doctors who are orthopedic surgeons, trauma and pain specialists and possibly plastic surgeons too. If you are at a teaching hospital, you will also see resident doctors who will wake you up first thing in the morning while doing their rounds. Keep track of which department they represent (orthopedic, trauma, etc.); then you will know who to ask which questions. It's okay to ask for reminders of who everyone is — they prefer that to talking to someone who is not sure!

As your recovery progresses, you may also meet hospital staff who are physiotherapists. They will want to get you “up” and moving. “Up” may mean sitting up in bed or in a wheelchair. You will learn to transfer in a sling and lift or with the use of a wooden transfer board, depending on your level of injury and how much pain and strength you have.

Professional Points: Intensive Care Nursing

What should I expect in Intensive Care?

The intensive care unit portion of one's journey is just that — it's intended to sort out, investigate and ultimately resolve critical, life-threatening injuries. That said, although important, it's a small piece in the grand recovery puzzle. Your care team is there to help stabilize and resolve life-threatening injuries so patients can go on to recover. When in acute care, it is truly too early to know the extent to which you will recover. The body needs time.

Who can I ask for help while in ICU?

Whether you think you need it at the time or not, seek out the department social worker. Even things such as paper work stemming from a motor vehicle accident (MVA) can feel very overwhelming on top of the injuries themselves. The ICU social workers are well versed in what needs to be done in the early days after an injury and what can wait. Many patients and family members have shared that social workers often suggest ideas and resources they may not have thought of.

Will movement cause more injury?

No two spinal cord injuries are the same. In acute care, you receive the medical treatment you need in order for your body to be stable, including your spine. At this point, ask your care providers to help you start moving. Movement is key in recovery – getting up and out of bed is important; so is dressing in your own clothes, if possible. As you start physical therapy (PT) and occupational therapy (OT), ask what “homework” you can do when they are not around, especially on weekends!

Can I have visitors in the ICU and Acute Care?

Having visitors will be determined by several things, including hospital rules. Usually only the very immediate family will be able to see you. ICU is a very busy, noisy place with many patients in the same room, only separated by curtains. Depending on your personality, injuries and coping abilities, you may or may not want people to visit. Although most guests are well intentioned, it’s important to rest and focus on you. Ask a family member or your nurse to ensure visitors minimize their visit time.

You will need to keep a person in your corner who knows you, your limits and your needs. They can advocate for you about noise levels, lighting, visitors and alone time. Remember that it is possible for some visitors to take more energy from you than they give back.

What if something else goes wrong with my body?

All SCI families and patients with injuries above T6 should know about autonomic dysreflexia (AD). Learn about the causes, how to prevent it, what signs to look for and how to alert your medical team when you feel a crisis is coming on.

Advance Care Planning is very important and applies to everyone. This can be facilitated through reflection and conversation with your nurse and social worker. It’s a way to enable your Substitute Decision Maker (person you entrust to give or decline consent for medical care in the event that you are not able to do so) with the confidence in knowing that they are enacting your wishes. It helps to know that if worst case scenarios come to pass, your wishes will be honoured. That is empowering.

How do we stay organized?

Keeping a notebook or electronic record may seem simple, but you will also find it to be extremely helpful! Keep it at your bedside; your spouse/partner/parents should keep one too. When questions arise, jot them down so when the specialist enters the room your questions are ready. It is so common for concerns to be forgotten in times of stress. Remember to record the answers you get as well.

Insights from the trauma care nurse practitioner: Amy Makish, BScN, MN, NP

“We encourage newly-injured people to have an active role in their recovery right from the beginning. Family and friends should not do everything for the patient; challenge them to do it for themselves. You don’t need to wait until rehab to start feeding yourself, getting dressed, etc. Start now. Family always wants to *do* for the patient, but should instead help the patient *do* for themselves.

Also — and this is important — don’t read and believe everything on the internet. It is good to google and learn, but then follow up with your health care team to understand what you are reading and how that relates to your situation. At this point, it is important that you know what the next days, weeks and months will look like. It’s time to ask about what the criteria are for getting into rehab and what will happen if a rehab bed is not immediately available.”

Insights from the ICU nurse: S.B., RN, BScN

“This is a life-altering event; your body will continue to heal as you leave the ICU. With time, and as the swelling is reduced, some function may be regained. Your ‘final’ answers pertaining to damage or injuries sustained might not come from ICU, but well after you leave our care. Hope is important! Take one day at a time. If that feels too overwhelming, then start with one minute at a time and build from there.”

Patients with spinal cord injuries will almost always have multiple doctors. You should ask each doctor what their role is in your care so you know what to expect. Whenever your doctor proposes a medical procedure/surgery, be sure to ask the primary reason for the procedure, what you can expect from the results of the procedure/surgery and also what the common complications are. This will ensure you are as informed and ready as possible.

What should I expect from the surgery?

The initial damage is done at the time of injury; traumatic spinal cord injury is not reversible with surgery. In many cases, surgical intervention is performed to prevent progression of the SCI. For example, if you have an incomplete injury, surgery can be performed to prevent complete paralysis. If any of your vertebrae were broken at the time of the injury, surgery may be done to stabilize the spine (involving plates and screws), without necessarily trying to improve the function.

You (or your loved ones) should ask your doctor before and after surgery for clarification to understand the primary reason for doing the surgery; understanding will allow you to have the most reasonable expectations for the outcome.

What questions should you ask your surgeons?

You will likely feel very overwhelmed, with information coming at you from many doctors. Don't feel that you must ask ALL questions immediately after your injury. You will have a long-term relationship with your health care team and you will have plenty of opportunity to ask questions. Most doctors will continue to see a patient with spinal cord injury for several years.

What is my prognosis?

Do make sure you ask your doctors about the preliminary prognosis. Your doctors will likely inform you that traumatic injuries are unpredictable; however, they should be able to offer you an educated opinion as to the expected long-term outcome. Their ability to provide you with an accurate prognosis improves as more time passes, so continue to ask.

Insights from the Surgeon:

Parham Rasoulinejad, MD, FRCSC, MsC

“Patients who have a spinal cord injury often underestimate what they will be able to do independently. You will have many resources over time that will allow you to live a happy and fulfilling life as a contributing member of your family and society. The journey to recovery will be very long and challenging, but with every challenge comes a new discovery of inner strength and perseverance.”

Respiratory technician

If you had chest tubes post surgery, be prepared to be followed by a respiratory tech. You are going to have to relearn how to cough in order to clear your lungs. With reduced core muscle strength you don't have the same “umph” needed to get phlegm up and out. The respiratory tech will help you with this. Wait until you sneeze for the first time — you'll look around and say, “Whose little sneeze was that?”

Who can I go to at the hospital to ask for help?

You are not in this situation alone. The ICU and trauma team will have a social worker for you to talk to. The patient is not the only one going through something awful. The family and loved ones are too.

Who should we involve in our team at this point?

In the acute care stage of recovery, you mostly just need hospital staff. You and your family are in control of your team and at this stage there is no need to involve outside case management, legal or insurance people in family meetings. This is a very personal time where diagnosis is still being discussed. Things will change when it comes time to go home, but that is not now.

It's not just the patient that needs help

You are not alone in this situation. Every step of the way, change is happening to everyone — children, partners, parents, etc. Everyone should access help, not just the injured person. This is often hard for families to do because they minimize their experience compared to what is going on with their loved one.

Families will need to look at their normal coping strategies while dealing with stress — exercise, journaling, talking to friends or professionals. Ask if those coping strategies are working and what else you can do. Children, especially, will seem resilient, but should be monitored over the long term because everyone's stress will affect their view of the situation and of their own life. Many families have never had to cope with something as major as a spinal cord injury and sometimes those families need the most help.

How do I cope when coping seems impossible?

Believe it or not, you will build resilience in yourself and in your team as time goes on. Yes, this will shake your belief of security in the world and create a feeling that you are not in control of your life. It may take your stress levels off the charts, but *you* are in control now. What happened to cause your SCI is over. Now you need to focus on each day and not think too far into the future.

Some of the things you are telling yourself may not be true (like about how you're going to cope), so talk about them, write them down and examine each thought by shining some light on it and asking: *Is that actually true? Do I need to have this worry?* It may not be true. Have this conversation with your social worker or psychologist and take control of your thoughts. Act on the thoughts that are true, shelve those that are not.

What about money?

While in hospital, everything is covered by OHIP if you are an Ontario citizen.

How do I deal with offers of help?

This is NOT your job. Yes, you will need help, but delegate someone else to manage those offers right now, if you can. People genuinely love to offer help and, in turn, it helps them feel better about your situation. Navigating the aftermath of a family tragedy often involves food; neighbours and friends will want to bring it, so let them. Your delegate can label it and put it in the freezer, as there will be days where nobody can cook.

Your delegate can also have a list of other tasks that need to be done. Welcome the help of others (such as church or work communities) to get things like gardening, snow clearing and child care, looked after. Hospitals are scent-free and, unfortunately, flowers often aren't permitted. Consider asking instead that money go toward parking or a coffee fund for those sitting beside your bed.

Insights from the Acute Care Social Worker: Bev Lewis, MSW, RSW

"Most of all – don't panic. Don't minimize the situation either, but panic will not help. There will be a lot of help to manage every step of the way. There is a lot of evidence to support that people can manage more than they think they can and can make more adjustments than you thought were possible."

What else should I expect during acute care?

Expect people to visit without an appointment, including legal and insurance people, friends and strangers. If your SCI was the result of an insurable accident (MVA or WSIB), you will, for sure, be visited by someone from the insurance company. This is the insurance adjuster and they will want every last detail. Also, keep in mind that material offered by law firms might not be unbiased.

A peer-support mentor (a trained volunteer who is living their life with an SCI) may also come to see you. Keep in mind that it may be too early for you to comprehend your future circumstances and the peer support conversation may best be had between peer and family/loved ones — it offers support and hope for families. Collect whatever information they have to offer, as peer support will be helpful when you are ready for it.