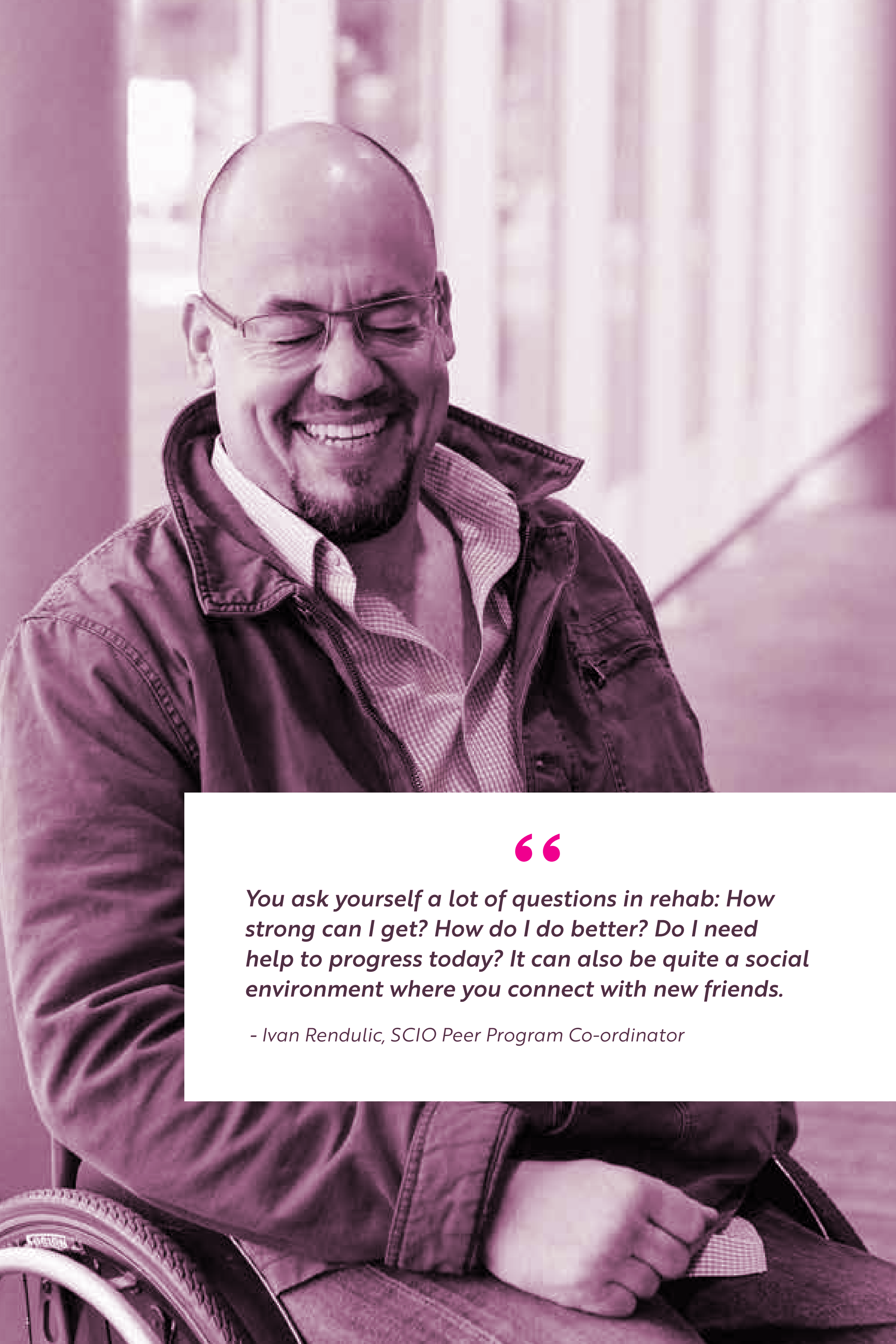
CHAPTER FOUR

Rehab



> “
>
> *You ask yourself a lot of questions in rehab: How strong can I get? How do I do better? Do I need help to progress today? It can also be quite a social environment where you connect with new friends.*
>
> *- Ivan Rendulic, SCIO Peer Program Co-ordinator*

WELCOME TO REHAB! … REALLY??

Staying in a rehabilitation hospital (specializing in spinal cord injury recovery) is just a stop on your way back to a full life. Your recovery will continue once you get home and will go on for as long as you force yourself to learn how to be more independent. For now, you are learning about your new body and how to handle it.

Up to this point in the Roadmap, the concept and the place we call "rehab" has not been completely or thoroughly explained. If you read "Julie's Journey: The Full Story," you will have a sense of what happened in my case, but it is not the same for everyone. Let's get you comfortable with the idea and the place of "rehab" before we go any further.

In the Province of Ontario, there are six rehabilitation hospitals that specialize in spinal cord injury care and rehabilitation: Lyndhurst in Toronto (part of University Health Network), Parkwood Institute in London (part of St. Joseph's Health Care London), Providence Care in Kingston, Hamilton Health Sciences Regional Rehabilitation Centre (located at Hamilton General Hospital), the Ottawa Hospital Rehabilitation Centre and St. Joseph's Care Group in Thunder Bay. It is also important to note here that all of these facilities also have people who specialize in caring for Acquired Brain Injuries which often, but not always, occur when the SCI has been caused by a traumatic accident.

Having been diagnosed with a spinal cord injury, your physician may refer you to the closest rehabilitation centre. As Ontario is a very big province, for some, this could mean making the decision to be far from home (for what could be months) in order to support recovery. This is not an easy decision to make — and yes, you do get to decide. Wait — what? Yes, you have a choice to go or not go. READ ON so that you know how important it is to go to, stay at, and put all you have into your time at rehab. The benefits will outweigh the challenges posed by the distance from home.

One thing is for sure — and I think you have a sense of this already — it is not going to be easy. Rehab is one of those times where "if it's not hard, it's not helping." The other sure thing about rehab is that you are going to be a completely different person when you leave compared to when you first roll in. And by completely different, I mean better. Not "better" as in you are going to walk away (although some do), but better in that you will understand your body and how to manage the functions that, at this point, seem very out of control. You will be physically stronger than when you arrived and you will have experts help fit you for a mobility device that suits you. You will know how to tell people what you and your body need in order to function well.

Peer Perspective

DIANE'S DECISION

When I was first injured, I didn't really grasp the many ways that my life would be impacted by my SCI. I also didn't understand the difference that SCI-specific rehab would have on my outcome. I was told that I should go to Lyndhurst, but I couldn't understand why I couldn't do rehab at my home hospital. Living in a remote Northern Ontario town, Toronto was very far from my home, my family and friends. I would be on my own if I went to Lyndhurst for rehab and I was afraid. My physiotherapist at the hospital played a big role in teaching me that there was a huge difference in what I would learn in my community hospital vs. what I would learn at Lyndhurst. Even though I really didn't want to go, I agreed to the application.

I remember the day I was transferred to Lyndhurst. I felt so alone, but right away I began to learn about how to take care of my body and how I was going to learn to transfer and get dressed. There were other people that were around my age, who were going through similar things. They had been at rehab a little while and had seen the benefits, so they welcomed and encouraged me. I can't stress how much my life began to change after I got to rehab. I got stronger and more independent. I was challenged by my health care team to do more for myself all the time. They provided me with the tools, information and support needed to get going; I provided the perseverance.

I can't stress enough the importance of going to rehab, even if it means travelling far from home. I was not the same person leaving rehab as when I entered.

Being away from home is never easy. Being far away from home is going to be challenging, but not insurmountable. Communication technology will help you stay connected to those back home and you will develop relationships with those who are going through the same thing that you are. Often these are the people who end up making the most difference in a person's recovery.

Get comfortable. This is where you are likely going to spend a lot of time, possibly months, so make it feel like home. Have your family members bring or send pictures, comfortable blankets, stuffed animal friends, snacks, a device and a headset. Oh, and don't forget earplugs!

Your level of injury and any other complicating health issues, including your age, will determine how much time you spend in rehab. You may be able (once you are strong enough) to go home for a weekend/home visit. Get as much out of your care team as you can — they are there for you. You will be a different person when you leave.

Professional Points: Nurses

You'll meet many, many nurses; however, you are likely going to have one primary nurse who is assigned to you. This is the nurse that you will spend a lot of time with and you should use as your "go to" person. Ask all your questions and learn as much as you can. Ask them to show you exactly what they are doing and why. When they are not around, write down the questions you have so you remember to ask the next time they are on shift. You will also see registered practical nurses (RPNs) and personal support workers (PSWs) while in rehab. Ask their names and what level of qualification they have because they may not always wear name tags.

Your nurse will be doling out your medications, monitoring your urine, measuring your vitals and, to an extent, helping you through your day. They will help you establish a bowel and shower routine and will talk to you about your pain. They can be the connection between you and your doctor by relaying messages to them for specific medical concerns. There will usually be a nurse who is the Unit Lead — if you think you are not getting the care you need, ask them for help.

Why are the nurses not doing everything for me? I'm paralyzed!

If they are a *good* rehab nurse (Certified Rehabilitation Nurse in Canada), they will make you do everything you can as soon as you are *almost* capable. Trust me, this is for your own good! It is their job to help you learn to be independent with your own care. Your spouse, parent or professional caregiver may not always be there when you need them to be. You have to learn what you can do by yourself or, if due to a high level of injury and you are not able to, you will learn how to direct your care providers.

I don't want to do *that*!!

You will learn (whether you want to or not) a lot about your body — much of which you have never thought about before. For some, the intimacy with which you will need to know your anatomy will be uncomfortable, but you really have no choice.

There's the easy stuff like how to do your own skin checks — those parts of your body that you cannot see easily and can no longer feel. You need to make sure you have no areas that are receiving too much pressure from your wheelchair or mattress. Transfers from one place to another can cause skin irritation, cats have claws and toilet seats can pinch! Pressure sores can develop into extremely serious, even life-threatening conditions, so it's important to learn how to check and position yourself to prevent them.

Then things get *more* personal.

I have to do *what*??

Your bladder needs to be emptied regularly (perhaps up to 10 times a day) and, if you have lost bladder control, it must be done with a sterile catheter. People with high level injuries and little hand function often use in-dwelling catheters, but for those who are able to, studies show that in-out catheters result in better bladder health. You will learn about medications that help with bladder spasticity and other ways of managing bladder health like supra-pubic ports and botox. Unfortunately, you will also learn about urinary tract infections.

Urinary tract infections (UTIs) may plague you for the first part of your new life. First, and most importantly, learn your signs. You will see changes in urinary function such as cloudy/foul smelling urine, incontinence (more than usual), fever (moderate), headache and fatigue. Most people also generally feel poorly. There are many non-scientifically proven methods for preventing UTIs. The proven ways to prevent UTIs are good hygiene, drinking lots of water and making sure you empty your bladder regularly with a sterile catheter.

Initially, your bowels will act like a beast that cannot be tamed, but eventually you will get those intestines under control, even routined, too. Depending on your type of injury, there are different ways of managing bowel movements. You'll learn the importance of wearing gloves, using personal lubrication, suppositories, milk of magnesia and digital stimulation. If you are not able to perform your own bowel care, nursing staff will help you learn how to direct your care in order to have an effective bowel routine.

The sooner you learn to manage your bladder and bowels, the sooner you will be able to wear your own underwear again! There is no need for you to continue wearing an incontinence brief if you are able to go accident free for several weeks in a row.

So what about sex?

Sex is on the minds of patients more than health care providers ever realized. Now, nursing staff understand the importance of talking about it. So ask lots of questions; after all, you have to learn a whole new way of being intimate with your partner and with yourself. Ask about position, lubrication, toys, aids and side effects. What people may not realize is that sex can lead to Autonomic Dysreflexia — not the outcome of an orgasm that you are after! A healthy sex life is indeed possible with an SCI and there are lots of places to find information and supportive resources for when you're ready. Read more on sex in Chapter Seven.

Who's in charge here, anyway?

Although it may seem that the nurses are in charge of your recovery, it's your body and you are the one in control of what happens to it. You need to listen to your body — and you need to help your care providers to listen, too. You have to advocate for your needs; try saying, "I know this is your job and you are telling me what you think is best, but my body is telling me... Can we try this... ?"

It's not so much a science as an art form. Learn about all the other options that are available for whatever issue you are having — someone, somewhere will have tried something different.

What do nurses really want families to know?

The nursing staff wants families to know that *you* also have a job to do. Your role in rehab is to step back, be a cheerleader and let the patient be in charge of their care. Let your loved one have the control — especially in cases where the patient is older or younger, children of seniors or parents of teenagers tend to interject. You need to let them make the decisions, ask the questions and do the talking. If you feel that your loved one is making the wrong decision, talk to the staff separately and say, "Is this appropriate?"

Especially in a traumatic event, where survival may not have initially been clear, you need to let them get as far along as possible — on their own. Often, families end up taking away the control, even though they are trying to help. Nurses are not always going to be there to help and neither are families. Step back and let nurses do their job of teaching. SCI will mean struggle; trial and error is how people learn.

Another reason to give space is because if you, a family member, are always hovering, the patient may not be comfortable to ask nurses questions, rest or just do what they need to do. So let them be. Allow them to struggle. Life is going to get to a new normal, eventually.

Insights from the Rehab Nurse:
Elizabeth Fox, RN, CRN(c)

"I don't get paid to do it for you, I get paid to watch you do it. Welcome to rehab!"

Julie's Journey

BLADDER & BOWELS

I distinctly remember being in my hospital bed in the trauma unit and watching the urine as it left my body through a tube connected to the catheter bag. I realized that if I took a deep breath I could actually "move" the urine to go down the tube faster. I thought that was pretty cool, but I'm a biology teacher, so I think words like "sphincter" are cool.

But my point is that I was getting to know my body in a new way. Before the collision that caused my SCI, I had a pretty good connection with my body; I knew when I was hungry, tired, hormonal, pregnant...

My SCI has required that I learn about my body in a whole new way — and be comfortable with it at the same time. Pre-SCI, bowels and bladder stuff happened without too much thought or organization. Now, dealing with it has become incredibly intimate, something that has required a whole new mentality.

While in rehab, the nurses were very excited about the possibility of teaching me how to use a catheter on my own. For a long time, I was not at all thrilled about it and put it (and them) off for as long as possible. But learning to do intermittent catheterization (pretty much anywhere now) has given me the independence to go almost anywhere, except for the odd house that doesn't even have a closet big enough for a person in a wheelchair to get some privacy.

The bowel stuff is a bit tougher to manage, but you will get there. It won't happen overnight; in fact, it will likely take months to get into a routine that you (and your bowels) are comfortable with. Shit happens. And at the beginning, in places and ways that you would not wish on your worst enemy.

But it gets better when (not if) you get more comfortable with your body. Pay attention to little signs, things that your body is trying to tell you, like foods to eat in order to avoid delays, how much (or what) to drink and medications that change how your body functions (like antibiotics).

Trust me, you are going to be sticking your (gloved) fingers in places you would never have imagined before. You may need the assistance of a nurse, or a professional caregiver; the more comfortable you are with your body, the easier it will be for them to help you. But you will get used to it, you will get better at it and you will start to develop the freedom you need to carry on with your life.

LOA: Leave of Absence

Speaking of struggling… Everyone struggles the first time they go home. An LOA is a way to learn what you don't know and yet have the ability to go back to rehab and say to your therapists/nurses, "What about…?"

You likely won't have nursing care 24 hours a day when you are home for good, so an LOA will help you "practice" being home. Some rehab hospitals have units that are designed for an LOA (called Independent Living Units) and you can ask to go home for a weekend, too. You will learn about the impact of travel (in a car, often for the first time), getting in and out of bed and just the mental stress of adjusting to the next phase of your recovery. You have to go home eventually, so why not practice that, too?

Julie's Journey

GOING HOME

Two months into my four-month hospital stay, I came home for a weekend. My husband and his friends had moved our bed to the main floor to make a new bedroom out of the former dining room. Other furniture had been moved to give me space to get around, but it was tight. Aside from all the physical discomfort I was still experiencing, the emotional toll of coming home hit me hard. I would never be able to walk around our property independently, enjoy the trees and help out with our large vegetable and fruit gardens. Even travelling up and down the long gravel driveway would forever depend on the season and the weather. Going home should have been joyful, but instead it really hit hard.

Professional Points: Physiatrist

A physiatrist is a doctor who is a rehabilitation specialist. They will have expertise in neurotrauma (SCI specifically) and acquired brain injury rehabilitation. They are the doctors who will have the most information about spinal cord injuries and will be able to answer all (or at least most) of your questions. They will stop short of any type of recovery prognosis, but they will give you their best opinion. While you are in rehab, see them as often as you can. Stop them in the hall and give them an update on your progress in therapy. They will also be one of your cheerleaders!

When you leave rehab, they will keep you as a patient for as long as you need their assistance. Keep a running list of questions that you have so you can make the most of your time at each appointment. You will need to talk about pain management, UTIs, bone density, blood pressure, physiotherapy, medication, emotional support and whatever else you want answers for.

Your physiatrist will have a lot of connections in their rehab community and they may be an excellent person to ask for recommendations. They will know from other patients what people have done who have had the most success and therefore they will be able to guide you in that same direction. Ask for recommendations by speaking to other patients as well; those who have had success (including legal) will be the best to talk to. Ask your physiatrist to connect you to others so you can build your community of peers.

Insights from the Physiatrist:
Keith Sequeira, MD, FRCP(C)

“Be sure to think about the long-term consequences of your actions. As you start your recovery, have goals for being active, maintaining your weight, managing bone density, shoulder strength, cardiovascular and general health. Making choices to play sports will be beneficial for your social life and your mental health, but think about the future and how you will maintain your fitness and your everyday life should you become injured. Investigate all types of treatments for physiotherapy, dealing with nerve pain, or if nerve transfer and tendon reconstruction would be helpful.”

Julie’s Journey

HBP IS AD IN SCI FROM UTI

One of the physiological anomalies of an SCI is the effect it has on blood pressure. Blood pressure regulation can become difficult if you have an injury of T6 or higher. You may experience low blood pressure (90/55) due to the lack of messaging to your lower body. No messages to the muscles means they can’t contract to help push blood back up to the heart and head. This often causes dizziness, feeling of lightheadedness and blurred vision. Although all of these symptoms are uncomfortable, they are not necessarily deadly.

The opposite is true of high blood pressure in SCI patients. This is what is known as AD — Autonomic Dysreflexia — which is caused by discomfort or pain that the body cannot sense or respond to. AD causes elevated blood pressure, which can lead to stroke, cardiac arrest or other deadly conditions.

It was three and a half years post injury before I really experienced the true effects of AD. It happened when I had one particularly awful UTI. The infection had caused my bladder to produce blood which, in turn, had started to clot. The blood clots blocked the catheters I was using and I was not able to empty my bladder. Of course my body did not like this, my bladder getting fuller by the minute, and I started to feel the effects of AD. My blood pressure was increasing, I was red in the face, starting to sweat and getting a really bad headache. By this point we were on our way to the hospital; I knew I needed help to get the clots out.

This was a scary time for me. At the hospital, I quickly explained my situation and they brought me into an exam room where they proceeded to use a number 18 three-way catheter so they could flush my bladder and suction the clots through the catheter at the same time. It took a serious amount of suction from a large syringe to get the clots out. It also took a couple of days (and some killer antibiotics) for everything to settle back to normal. Do not mess around when AD happens. Figure out the source and get it looked after ASAP

Carry a card in your wallet, one that explains AD, since not all emergency staff will understand the condition.

General Practitioner (GP)

The GP is your family doctor while in the hospital. Ask them your medical questions; they will manage your medications and help with the diagnosis of any secondary complications (like UTIs and skin breakdown). Together you, your physiatrist and your GP can determine which route(s) to take to help manage your pain.

DIET MATTERS

Professional Points: Dietitian

Now you need to prepare your body to be ready for what comes next — rebuilding. How much you will recover is anyone's guess, so you have to provide your body with the nutrients it needs for the best recovery possible. That is where a dietitian can help. Hopefully, you will have the help of a professional while you are in rehab, so ask all the questions you can.

How much should I be eating?

As you move from acute care to rehab, your body is likely still in a "hypermetabolic" state. This means that your energy needs are higher than usual because the cells and systems of your body are trying to repair the damage that has occurred. BUT this doesn't mean you can eat whatever you want; this is when every calorie you eat counts and those calories need to be high quality nutrients.

There will come a time in your rehab where your choice of calories can mean the difference between weight gain and muscle loss. Weight gain leads to increased stress on joints and makes recovery more difficult. If you gain weight when you have paralysis, it means you have more body mass to move around using just your arms and shoulders.

Does what I eat affect the pain I have?

There is a lot of new research showing that there is a connection between inflammation and pain. Often, inflammation in the body is connected to food choices. Your diet could very well impact the amount of pain you are feeling. Nerve pain is something that is very difficult to overcome — you need to do whatever you can to make a difference. If changing what you eat can reduce your pain, why wouldn't you try that?

How does my diet affect my bowels?

While in rehab, you will be figuring out how your bowels work and what routine works best for you. Your rehab dietitian will help you understand what types of food (and fibre) you need to eat and they will also be able to help you determine what types of medications you might want to talk to your doctor and dietician about.

Before your injury, you likely knew to "eat your fibre for good gut health," but now it really makes a difference. Eating foods that are high in both soluble and insoluble fibre will help move material through your intestinal tract — and this is what you really need now that your intestines don't work the way they used to. Ask the professionals that are working with you for help — specifically, what are the foods that will help your bowels? Remember that every SCI is different, so what *you* need to eat may be different from that of the patient in the next bed.

What is the connection between skin health and diet?

Due to reduced circulation (caused by paralysis), your skin will receive fewer nutrients and less oxygen. If a pressure wound occurs, even *less* oxygen and fewer nutrients are delivered to the area and essentially the skin is dying. This is why putting high-quality nutrients into your body is so important. Healing skin requires more than just relieving the pressure to the area; you have to optimize the quality of fluid and nutrients getting there.

In order to fill that hole in your skin, you need the raw materials of proteins, vitamins and minerals and you want those to come from your diet, not from what is stored in your body. Muscles are already being broken down, impacting recovery and strength. Think of it like a pothole; if you fill the hole with sawdust and cover it with duct tape, it will be closed, but you know it won't stay that way. The raw material needed to fill the hole must be of good quality. Research shows that the strength of skin two years post pressure sore is only 70% the strength of the skin prior to break down — and that is when it heals under ideal conditions. So remember, garbage in, garbage out.

But this should be the time for comfort foods, right?

No. Although you may crave comfort foods, every calorie you eat should be of high quality. Salt, sweet and fat feel better in your mouth and to your brain, but they don't help your body. You can't afford wasted calories. Focus your eating on nutrient-dense foods. They should have high protein, good fats and lots of antioxidant qualities. Eat nuts, fish, eggs, seeds, berries, leafy greens and colourful vegetables. Although you may spend most of your time thinking about walking again, getting there requires high-quality foods.

Insights from the Dietician:
Chris Fraser, RD

"Most patients are focused on therapy and how to get home. They tend not to think about the food that they are eating, especially because comfort food can feel so good! During rehab is the time to think about what you need to eat and to ask for help. Start planning and talk to your people. They will want to bring treats for you to 'feel better,' but you need to be firm and ask for their support in changing how you eat. You need to fuel your recovery — your skin, muscles and bones need as much help as you can give them!"

MENTAL HEALTH

Professional Points: Psychologist

Some people will be more comfortable than others when it comes to speaking with a professional. Whether you realize it or not, your life has been turned upside down. Talking about it, learning relaxation techniques like meditation and, most of all, talking about feelings is more important than ever. Depression is a reality for many people with an SCI. Not being able to do many of the activities that you used to do will take some adjustment, so discussing ways of coping will be very helpful. Even though you will have spoken with a psychologist at least once while in rehab, don't think you are done — talking can sometimes be the best medicine. Your mental health is so important and depression can lead to increased pain. Being reminded that what you are going through is difficult is often helpful to move closer to acceptance.

Your discussions need to be open, honest and in a place of trust that allows you to feel vulnerable. That is why your choice of therapist needs to be carefully considered. While in rehab, you likely had a psychologist on your care team, but heading home you will need to find one in your community.

Do I need therapy?

Many people have found it a crucial step in their recovery. Suffering an SCI is a loss. Not only a loss of physical mobility, but it can also be a loss of self, roles, relationships and independence. The process of going from walking to not walking is akin to other grieving processes. Grieving is not a linear process and emotions will come and go; remind yourself that this is normal. Expect to have a fluctuation of emotions: hopelessness, fear, anger, determination and devastation, to name a few. Talk to others who have experienced SCI about these emotions, as a way of learning that these experiences and emotions are normal. Feeling isolated and alone can be one of the worst parts of experiencing loss. That is where talking comes in. A professional therapist can help you find ways to adjust to your new life, your emotions, thought processes and can help you problem-solve about how best to adjust to your new life and relationships.

How do I find a psychologist or social worker once back home?

Start with your family doctor. If you are in a Family Health Team, then most likely you will have a therapist on that team. Your doctor may recommend you start there, see how you connect and then decide if you want to continue to see them. It should not take too long for you to decide if you want to work with them (maximum two sessions). If you are not comfortable, feel you don't connect or relate to that person, try someone else.

Does my therapist need to have experience with SCI?

It is not essential that your therapist have experience with SCI, but it would help. Having an SCI places you in a new culture, one where terms like *bowel care* and *injury line* are new. Experience with SCI also leads to an understanding of how "excuse me, I have to pee" means that it has to happen *now* and that a supposedly accessible washroom often is not. The experience could be with former patients who had an SCI or it could mean experience in a rehab facility. All this background knowledge will help move your therapy along more smoothly, with less need for explanations from you.

How do I pay for a psychologist or social worker?

Fees for services can range depending on where in the province you are located, but the average is $125/hour. If your injury is the result of an MVA or WSIB, then insurance will cover this expense until you settle with the insurance company. If you have work benefits, they should also cover most, if not all, of the cost. If you have neither option available to you, *DO NOT GIVE UP*. OHIP will pay for the services of a therapist who is a member of a Family Health Team. Again, ask your doctor.

Should my partner/Family Member also talk to someone?

Your immediate loved ones can benefit from connecting with a psychotherapist or social worker as well. This loss is also theirs. They are experiencing many changes in their lives because of your SCI and you are not the person to guide them through these experiences and emotions. You are too close to the situation to be able to support them in an appropriate and healthy manner. Family caregiver fatigue is a real thing; emotional support from talking with a therapist is one way to help prevent this from happening.

What will we talk about?

Each person's journey will have unique challenges and aspects that should be addressed; however, there are a few core areas that you should cover with a therapist to ensure optimal emotional recovery, including relationships, emotions, sleep, body image and returning to work, to name a few. Because SCI and acquired brain injury (ABI) often go together, your therapist should also be informed of any ABI symptoms in order to address them during therapy.

Insights from the Psychologist:
Erin H. Ross, PhD, CPsych

"Make sure you are monitoring your sleep. Sleep aids in physical and emotional recovery and can be the difference between feeling determined or feeling devastated about progress and setbacks. Nutrition and movement are also powerful in terms of their impact on our mood. Recovery will have many physical demands that require our bodies and minds to be as healthy as possible. In addition, socialization is key to emotional wellness. Loss and physical changes too often result in isolation from friends, family and other social interactions. We are social beings. We find meaning, happiness and a sense of calm through our interactions with others. You will need this more than ever during recovery (and adjustment to your new life). In short, eat well, sleep well and be social."

Professional Points: Social Worker

While in rehab, you will have a lot to talk about. Your social worker will help you figure out what you need for discharge, for your physical surroundings and also the people to involve in your at-home rehab. They will also just be a good person to talk to.

Why do I have a social worker?

Aside from the nurses, the first person you need to talk to is your social worker. Rehab inpatients are assigned a social worker as a part of the team. Even if you don't have any specific questions, all you have to say is, "Where do I start?" or "What do I need to know?" That is the job of the social worker — to help you figure out what the puzzle pieces are and how to start putting them together. You need to learn how your life has changed and what it is (likely) going to look like when you leave rehab. This way you will be as prepared as possible when the time comes to leave.

How will I manage finances?

Unless you're independently wealthy, you will need money to buy equipment, supplies, pay for physiotherapy, maybe renovate your home, buy a new car and purchase clothing that is wheelchair friendly. If your SCI was the result of a motor vehicle accident (MVA), a workplace accident (WSIB) or another kind of accident covered by insurance, after lots of paperwork, insurance will pay for many (if not all) of your expenses. Your social worker will help you navigate the beginning of this system; it is one that will continue long after you leave the hospital.

If you don't have insurance, your social worker will help you understand and start the process of getting help from a case manager, Community Care Access Centre (CCAC), work-related insurance, Ontario Disability Support Program (ODSP), Employment Insurance or Ontario Works assistance. Help does exist. They will help you with the applications and the paperwork — it's a great idea to start keeping a binder!

Help me with housing!

You may need to get creative when it comes to finding housing. If your SCI means that you will be using a wheelchair, chances are that your current living space is not very accessible. There is a very serious lack of accessible housing in every community, so if your goal is to be independent, you are going to have to choose — renovating, moving or considering some kind of long-term care facility until other housing becomes available.

How to find social support, community support and advocacy

You are not alone. Your social worker is there to listen. Talk about how you feel and how angry you are — it is a necessary part of recovery. You are going to need to grieve your loss, regardless of what happened to cause your injury. Having an SCI will likely be the biggest adjustment you will have in your life and you will need a sounding board to voice concerns about your future. Your social worker will listen and will be your advocate. They will help you find the resources you need and help you speak to your doctors or therapists so you are all on the same page. Your social worker will also help you connect with the community partners that are there to help you with your needs. Family members and friends are also grieving your loss. They will need support as well and should not be afraid to ask your social worker how they can get help.

What is a team meeting?

Your social worker will set up a team meeting with anyone involved in your case — your doctors, nurses, therapists, case manager, family and social support (perhaps even legal and insurance personnel). Everyone at the team meeting has the same goal in mind — for you to gain as much independence as possible and be ready (with funding in place) to leave rehab when the time comes.

***In cases of WSIB, your WSIB Social Worker will set up the team meetings, prepare medical reports and liaise with WSIB to get as much organized as possible before you return home. WSIB has a specialized team that is accustomed to working with people who have had catastrophic injuries.*

Insights from the Social Worker:

M. Jean Sommerdyk, MSW, RSW

"My role is to help patients find what they need. Whatever the situation, even when it seems complicated, we will help find the community supports required for when it is time to leave rehab. Ask for help; you do not have to go through this alone."

THERAPY

In rehab, you will have many people come and go — nurses and nursing students, visitors, specialists — but the one constant will be your therapists: physiotherapy (PT), occupational therapy (OT) and speech-language pathologist (SLP). You will get to know each other well. Trust them; they have your best interests at heart. Confide in them — your concerns, questions and fears. They will have the experience to help you or will know how to find what you need.

Professional Points: Physiotherapy (PT)

You may have already started doing some physio in the acute care hospital (like trying to sit up, or working on hand flexion), but if you were there only for a short time, this may be your first introduction to what physio is all about. At rehab, you will likely see your physiotherapist five days a week for between 30 minutes and an hour. You are going to get to know each other well!

How is physiotherapy going to help?

You won't always enjoy it, but deep down you know it is the right thing to do! Your PT will help you learn how to work on your mobility gently, prevent further injury and gain strength and balance. You'll learn how to stretch muscles carefully and reduce contractures in your joints. Physio also helps with blood circulation. You will start with conversations about the activities you did pre-injury and your PT will help you understand the process of working through many different stretches or exercises to reach milestones. Specifically important to work on are core strength and posture — being seated all day requires this.

What is Activity Based Therapy?

Hopefully you will get opportunities to do Activity Based Therapies. These activities work to mimic and reinforce normal movement patterns such as walking or cycling. Technologies like robotic exoskeletons were created to allow repetition of normal muscle action, with the hope of reinforcing that movement.

Julie's Journey

ROBOT GOALS

From the very first day I rolled into the physio gym at rehab, I knew I wanted to get into the Lokomat. There was a young woman up and "walking" in it and she looked so happy. I asked my physiotherapist assistant (PTA) about it and once I learned that it was not something that I could just get up and do, that robot became one of my goals. Before I was able to be up in that machine, I had to learn how my body managed blood pressure as well as muscle spasticity — I got "trained" on the tilt table. Along the way, though, I came to understand the benefits of robotic therapy — it wasn't just for the fun of being upright. There is a great amount of research and understanding about the physiological and psychological benefits of robotic therapy. It doesn't just make you look cool. It feels fabulous to stand upright, it's good for your bones (weight-bearing activity) and you can give and get a hug while standing.

What is FES?

FES stands for Functional Electrical Stimulation, a technology you should try to get access to. FES stimulates muscle groups (similar to a TENS machine) through the input of electrical stimulation to the nervous system. Many pieces of FES technology (typically cycling ergometers) can also be purchased for home use, which allows for more opportunity to use it. Typically, FES is used for leg, buttock and abdominal muscles, but is also used for arms and shoulders. FES may help with bone density, as well as maintenance of (or even an increase in) lean muscle mass, decreased fat deposits, improved circulation and cardiovascular conditioning. Some people also report decreased spasticity. If you have insurance, your company should back the purchase of FES — don't accept "no" as an answer to your request.

Julie's Journey

T4 SISTERS

I was lucky to be able to attend rehab as an outpatient. Parkwood has a gym that has very reasonable membership rates that include use of the FES bike. With four bikes in a row and an hour of literally being stuck there, you have time to make conversation and get to know one another. It just so happened that my Thursday time slot coincided with three other women who also had T-level injuries. We were the T4 Sisters; meeting weekly to share what was new, give and take advice. It really was one of the best things to happen to me. Over time, even though I had an FES bike at home, I still went to Parkwood to ride there. It was more than just the physical therapy; it was the social time, advice and camaraderie that made me do the three-hour drive (round-trip) almost every week. It became an essential part of my therapy.

Should I continue physiotherapy when I go home?

Your body still needs lots of help as it heals. At this point, it is important to remember that YOU are still the most important person in your recovery. You have to be comfortable with the therapist you choose. Once you get home and are settled, you will need to make a new routine for your physio. No longer will you have someone setting up your therapy time and writing it on the board beside your bed. Physio, once you are home, is even harder than in rehab because now *you* have to make it happen. You have to find a therapist, arrange to get there as often as you can and work hard.

How will physiotherapy continue to help me?

Physio is your key to recovery — because you *will* continue to recover. Your balance will improve, which means you will be able to reach closer to the floor and feel comfortable doing so. Your manual dexterity may improve and you may be able to fold laundry. Your blood pressure will level out more quickly and you'll be able to stand in a standing frame for longer. Your upper body strength will improve so you can do transfers that you may have not thought possible. Every little bit will make a difference. Given even a small chance that your neural pathway will be restored, making your body try to work is the only way to know how much recovery you will get. You have to try.

How do I continue to do physio when I get home?

Finding the right physio clinic is key to this success. If you live in a larger centre with multiple clinics, spend some time asking around. Who has experience working with an SCI? Who has had positive experiences with the people at the clinic? Who has been able to see results in terms of recovery? Ask everyone! This will be one of the most important decisions you make about your recovery. You don't have to stick with a certain clinic or therapist if it doesn't feel right. You can also have a kinesiologist visit you in your home to help you with your exercises or they can meet you at a community pool. Water therapy is also very valuable, to both mind and body.

Once home, use what you have learned in therapy — such as posture, body alignment, the proper way to roll or transfer etc. — and implement them in your everyday life as much as you can. Try not to allow yourself to do things the easiest or quickest way if you know it's not how your body would typically move. Your nervous system is constantly learning and changing — you have the best chance for your system to relearn the proper patterns if you are practicing them more than just during your therapy sessions. This can be exhausting and frustrating, but it is important.

What type of physio equipment do I need?

Although physio is your key to recovery, this does not necessarily mean it will get you up and walking. But there are many ways to keep recovery happening — and they don't have to cost a lot. Strengthening your core, shoulders and arms will be your means to be as independent as possible. Start with a stretchy band and set up a plan to use it every day. If you can get out of your chair, do exercises on a mat or physio bed. If possible, start out using light hand weights and pulleys. All these things will help you with transfers, dressing and even cooking. Having access to a standing frame is a good idea (at home or at a physio gym). It will help with joint loading and some people report improved bladder/bowel function. Standing on your body weight also can help with bones and bone density.

Julie's Journey

FOUR YEARS AND STILL WORKING ON IT

It's been four years since my injury. In those four years, I have been lucky to have physiotherapy at least one day a week. Some weeks I have had energy to work hard, others, not so much. But, every once in a while, I get to say to Marc and Bill, "I wasn't able to do this before, was I?" Some things seem very trivial, like putting two hands out in front without falling forward. But others lead me to think that there is more to come. Which makes me want to tell you not to give up. You don't know what you are capable of until you try and try again. No matter what doctors say, you won't know what your body can do (or re-learn how to do) until you make demands and have higher expectations. I plan to continue my weekly therapy so that I am as strong as I can be in my core and shoulders — it makes everyday tasks (like transfers) easier.

Insights from the Physiotherapists:
Bill Glassier, BSc, PT & Marc Pittock, BA (Kin)

"Therapy is hard. There will be days that you're not going to want to do it and days you feel defeated and exhausted or are afraid that you're never going to improve. It's okay to have a pity party (for lack of better words) for a little while, but then get back up and keep trying. Therapy is meant to be challenging. If it doesn't challenge you, it won't change you."

Insights about robotics therapy:
Stephanie Cornell, MPT

"There are a lot of pieces of equipment available that promote walking and enhance mobility post SCI. Find out what is right for you. Your therapist will make recommendations based on the evidence of the recovery of your nervous system. Early on in recovery, it is important to focus on flooding the nervous system with deliberate, meaningful sensory information."

Julie's Journey

JUST KEEP SWIMMING

For me, being in the pool was the most freeing experience. It got me out of my chair and I didn't have to rely on someone else to be active and try to move my body. I was a swimmer before my accident, but you don't have to have been to try it out. Ask your therapist to help you. Many rehab locations will have a pool and someone certified to do pool therapy. It's hard to say for sure how much, but a lot of my muscle recovery is from being in the water. You will be able to do things in the water that you can't do on land — yet. That is the surprising thing; if you can move this particular muscle in the water, then you can work on getting it to move on land. Swimming is also a fabulous cardiovascular activity and you won't overheat while doing it!

Peer Perspective

MICHELLE'S STORY (C5-C6 INCOMPLETE) — FOLDING SOCKS JUST FOR FUN

I didn't have a lot of hand function when I came home from physio, but I have been working on gaining strength and dexterity ever since. I work with a kinesiologist every week and together we try to do new things. Instead of just traditional exercises, we are doing things that have improved my hand function, but also have meaning. I even made my own video that shows how I can now fold laundry and even socks! I know that all the work I have done to improve my arm and hand strength and function have led to me being able to hold my new grandchild.

Professional Points: Occupational Therapy (OT)

What is OT?

The goal of occupational therapy is to help you become as independent as possible prior to your discharge. Your first visit to OT will involve being assessed by the therapist who is assigned to be on your team. They will assess your strength (active and passive) and your range of motion (shoulders to fingers), as well as your trunk balance. You will be asked to describe your pain and your skin sensation will be tested.

What kind of therapy will I receive in OT?

Your level of injury will determine the type of therapy that you will receive. If you have a thoracic or lumbar level injury, you will work on core strength and balance as well as shoulder and arm strength. With higher level injuries (high T-spine and C-spine), you will be helped to learn how to find a pain-free range of motion for your shoulders, arms and fingers. You will also work on hand and finger strength, dexterity and co-ordination. OTs will help you learn the benefits of using finger/hand splints and aids for holding things (like spoons). You will learn how to do things that you used to take for granted like sitting up independently or scratching the top of your head!

No matter what level your injury is, OT will also assist you with pain management through stretching, range of motion, strengthening, acupuncture or acupressure (using fingers on pressure points) and body positioning (such as in your chair or in bed). As you improve and gain strength, your therapy will be altered to work on becoming independent with activities of daily living (ADL).

What are ADLs?

Activities of Daily Living. As mentioned before, you will be learning how to do all the things that you learned when you were a child, like getting dressed, brushing your teeth or eating. There is a real knack to learning how to pull up your pants while sitting on them! You may need to learn how to hold a stylus or a spoon for cooking. Transferring into your car (or the tub) is also a big task to work toward. The more you can learn in rehab, the better off you will be when you are discharged to go home. In addition, you may be prescribed an aid or piece of equipment that will help you achieve your ADL.

Life at home

In OT, you will learn what equipment you may need to have at home. You will need to evaluate your home access, sleeping area, kitchen and bathroom. Knowing what support you have at home and your level of function will help your OT know what you need to work toward. If your rehab hospital has an Independent Living Unit (ILU), you should take the opportunity to try to live on your own for 24 hours. This will give you insight into what you still need to work on.

Pain and skin education

While you are an inpatient, you will be taught various techniques for pain management and for monitoring your skin. There is a lot to learn about pain management and everyone's experience is different, but it's important to talk about it regularly with your medical team.

For skin management, get yourself a small mirror that you can use to look at the parts of your body you are sitting on. Daily monitoring with a mirror is important; be aware of ankles, seams on clothing, pressure points from bony protrusions of your body and changes in routine which can all lead to pressure sores. Protect your skin at all costs. Pressure sores can easily become infected and, because of decreased circulation (due to your SCI), healing takes much longer than normal and can lead to more serious conditions. SCIO has produced an excellent publication on this subject: *Preventing and Treating Pressure Sores.*

Do I need OT once I’m at home?

You may need a different OT once you are back at home. It is the job of this OT to assess your home and help you realize what appropriate goals are once you get home. Some people dream big and want everything to happen at once; others don’t realize what they might be able to do. Safety is key; once you are home, you will want to be as independent as possible and that can only be accomplished if you have confidence and strength.

Not everyone needs or can afford an OT. If you have one once you’re home, make sure you are clear about the skills you want to learn: cooking, driving, working, playing with your kids — your OT will analyze the activities you want to do and teach you modifications so you can be successful. Once you are settled back into your home, your OT will help you make plans for returning to work or school. They will also have resources for parenting with an SCI, coping and time management skills and helping develop healthy habits such as skin checks, regular exercise and a healthy diet.

Choose an OT who is familiar with your type of case

Your OT must be familiar with the systems where you need to get funding; for example, if your only option is OHIP and government-funded programs like the Assistive Devices Program (ADP), make sure you have an OT who knows how to access these services. They must also be able to write persuasive application letters to programs from which you need help. Alternatively, you want to make sure you have an OT familiar with the Statutory Accident Benefit Schedule (SABS) and insurance processes if you were injured in a car accident. Your OT will be a big part of writing your treatment plans for insurance purposes.

Julie’s Journey

STURDY UNDERWEAR

When I was in rehab, my Occupational Therapist was a highly knowledgeable, strong and soft-spoken man. I distinctly remember a conversation about clothing choice. We talked about comfortable pants that don’t have seams, shoes that don’t dig into feet and sturdy underwear. Sturdy underwear?? I had not really understood what that meant or why “sturdy” was the adjective chosen. But now I know. When it comes time to use a catheter on the toilet and you have to pull down and up your underwear while sitting on it at the same time, you will understand that sturdy is what it needs to be; otherwise, you’ll put your thumb through the lacy bits and they won’t last long at all!

Insights from the OT: Gary Lee Tai Fuy, BSc, OT

“Do not compare yourself to your roommate or anyone else in rehab. Wondering, ‘When can I achieve that?’ and ‘Why can’t I do that?’ will only get you down on yourself. People will have more or less severe injuries and different American Spinal Injury Association (ASIA) scores. Age, previous fitness level, other injuries and medical conditions will complicate your achievements in therapy. Making comparisons can cause you to become angry and lead to depression. Keep a list of your own achievements and watch the list grow!”

Recreational Therapist

More than likely, you will have to find a new and/or modified version of the recreational activities that you did pre-injury. Many things can be modified like cycling, hockey, skiing, bowling and tennis — it is just a matter of finding the right person to hook you up. Your recreational therapist will show you variations on different sports and will try hard to help you find something you enjoy. Remember that, as you recover and gain strength, a greater variety of activities will become possible.

For people who participated in sport before their accident or injury, going home can be a reminder of all the activities they are not able to do any more. The soccer cleats may be where they were left and the hockey equipment still laid out on the floor in the basement. Everywhere you look, there will be stuff from your old life. In time, you will be able to deal with it and you will. Nothing will be the same as it was before, but you will find a new normal.

Speech-Language Pathologist

A Speech-Language Pathologist (SLP) may become a part of your care team if you had a head injury. Concussions often lead to difficulties (slowed speech, word recall, etc.) that can be tackled with therapy. Educating patients and their families upfront about the potential of a co-existing acquired brain injury (ABI) is important because family members may see changes in their loved one and not know why. You may be advised to have cognitive communication testing and subsequent therapy to help mitigate the effects.

PEER SUPPORT

The importance of finding a peer (or several) cannot be overstated. Spinal cord injuries are unique to all others and the need to connect with someone who has lived through it is SO important. Whether you find a peer on your own or are connected with one through an organization like SCIO, you will benefit from the knowledge of what they have already been through.

Why do I need a peer?

It's not just the knowledge that will be shared that is important, it is also paramount for your mental health. Just talking to someone who has been there lifts a weight off your shoulders.

How do I access Peer Support?

Peer support is invaluable. When you find it, you will have the opportunity to talk candidly with someone who has "been there." They can relate to what you're going through. It's important because you will meet people who have sustained an injury and gone on to live a fulfilling life.

A Peer Program Co-ordinator from SCIO will help match you with an individual who can share personal experiences, help you gain more confidence and understand the little details and the big picture of living with a spinal cord injury.

SCIO will help you make arrangements to meet with a peer support volunteer in person or over the phone. If the match doesn't feel comfortable, they can help find you another option. If you are not currently an SCIO community member, it is easy to register on their website at **www.sciontario.org/join**. Not all personalities and circumstances align. Do your best to find a peer before you leave rehab, because there is a lot to talk about before you go home.

Julie's Journey

SUPER DAVE

I met Dave Willsie when I was about a month into my rehab at Parkwood. He had been asked by a mutual friend to stop in and see me, so I was not expecting him. It turned into the most memorable visit of my whole time in recovery. Dave was a guy living his life with a C-spine SCI (C6 Incomplete), using a manual wheelchair and running his own lumber business with his brothers. Did I mention that he was the team captain of the Canadian Wheelchair Rugby Team?

But it wasn't the celebrity that I remember most. It was Dave, just a guy in the same boat as me. We had only just met, but we talked about everything — nothing was off the table. He made me feel comfortable and I knew I had to be brave in order to ask some questions about stuff I was concerned about. Catheter stuff, bowel routine, going home, work, relationships, sport and the importance of peer support — we talked about it all.

Dave was injured when he was 27. He learned everything he needed to know about living life with paralysis from his rugby teammates. They played together, rode roller coasters together and travelled on all the "accessible" airplanes, staying in all the "accessible" hotels around the world. There is a lot to be said for team sports.

Julie’s Journey

NEW “SPORTY” FRIENDS

I have made some amazing friends by trying new sports. Well, I guess the sports are not new to me, but I have a new way of doing them. Skiing, biking and kayaking are all things I have done before, but doing them all with your arms (and little core) sure makes them challenging. My point, though, is if I had not given them a try, I would not have met these amazing women who have done so much with their lives, regardless of the fact that they have a disability. So give it a try; you never know where it will take you and who you will meet along the way.

Peer Perspective

MICHELLE (C5-C6 INCOMPLETE) AND YOUTUBE

When I got home, I kept talking to the SCIO peer volunteer, but I also wanted to find a community of more peers. Because I couldn’t get out on my own yet, I started searching things up on the internet. What I found were a lot of SCI peers on YouTube. I am so thankful to all the people with quadriplegia who opened up their lives and shared how they do things. Everything from how to hold a fork by weaving in between your fingers to applying makeup.

It’s a mind set — I didn’t think I would be able to travel until I saw that other people like me were doing it. We went to Florida and it was that first trip that helped me realize that I am capable of using a manual chair, not just a power chair. My YouTube peers gave me something to do that was constructive — research. It fed my desire to learn how to overcome the challenges that I was facing. It gave me hope.

SKILLS TO KNOW BEFORE YOU GO HOME

Going home means, essentially, that you are on your own. It's going to be challenging, no matter how you look at it. But it will be less so when you know how to be prepared. Here are some things to know, ask about and work on before you leave rehab. Have an honest conversation with those you are going home with — the list is long, but by this point in your recovery you will be able to answer a lot of these questions.

Do not read this list until you are ready; otherwise, you may find it overwhelming. As you start to talk to SCI peers, these are the topics you want to ask them about.

Transfers

- You will transfer often, more often than you think!
- You will go from chair to: bed, toilet, shower/tub, commode, car — and back again.
- Do you need a transfer board or lift?
- How much assistance do you need to transfer?
- How will you get up off the floor? This will happen — what is your plan?

Dressing

- Some people dress in bed, others in their chair or on the toilet.
- Choose stretchy clothing whenever possible!

Medications

- This will take up more time/brain power than you would expect, so plan on using a system when you get home and stick with it until you are comfortable making a change.
- Where will you keep them, organize them, keep track of what you have taken and when?
- Do you have a system for re-ordering and getting them to your home?
- Do you have a plan for days when pain increases and you need to keep track of any increase in medication you take?

Eating/drinking

- Shopping, food preparation, eating, clean-up, carrying hot food/

beverages — what do you need help with?

- What to eat for weight management/bowel health?
- How much fluid to drink?
- How to deal with swallowing difficulties?

Grooming

- Washing, shaving, hair care, cutting finger and toe nails. Can you do these things independently?
- Who will help you as you are learning how to manage on your own?

Bowel care

- Requires transferring to the toilet/commode, bowel manipulation, clean-up (wiping).
- What is your plan for bowel accidents (which will happen when you get home)?
- What equipment/supplies do you need and where you will get them from?

Catheterizing

- How do you position yourself for this? (bed, toilet, chair…)
- What equipment/supplies do you need and where will you get them from?
- What is your plan for getting urine to the toilet if you use a collection jug?
- Getting pants back up (down is easy!) — have you learned this skill?
- How to progress to more independent bladder care (e.g., what's next so I can: leave home, shop, travel)?
- Can you tell when your bladder is full? Do you have a schedule?
- What are the signs that you have an infection?

Skin

- Can you check your own skin for scratches, sores or redness? All of your skin?
- Can you reach your feet to look at your toenails or cracks between your toes?
- What is your plan if you need help with this?

- Do you have an assistive mirror?

Mobility & Transportation

- By wheelchair: can you wheel yourself around in your manual chair?
- Do you have the strength/balance/co-ordination?
- Do you need help when you leave home?
- Can you safely operate your power chair and recharge it?
- Can you examine your chair for damage and inflate your tires?
- Do you have access to public transportation and can you access it independently?
- Do you have a car/driver? Can you (or do you plan to) drive on your own?
- Have you applied for a parking permit for your vehicle?

Communication

- Do you need assistance communicating to family/friends/medical staff?
- Can you make your own appointments and remember/record what you discuss?
- Do you have a method of recording and being reminded of appointments or other events (even bowel care/catheterizing)?
- Who will you speak to when you need help with your mental health and emotional well-being?
- Do you need help dealing with legal/financial assistance/returning to work? Who will you speak to?

Housekeeping

- In your living space, do you have a plan for cleaning, laundry, changing sheets, vacuuming, organizing, getting the mail, yard care/snow shovelling?
- Do you need help with pet care?

Autonomic Dysreflexia (AD)

- Have you learned about Autonomic Dysreflexia?
- Do you know what to look for when it comes to AD-related changes in your body?

- Have you noted how to describe your "normal" appearance (such as your normal blood pressure), so when changes happen you have a basis for explaining to medical teams how things are different?

Sex

- Have you talked about sex with your therapist or nurse/doctor?
- Are you talking to your partner about it?
- It will happen; be prepared for figuring things out.
- Do you have access to resources and information about sex and SCI? Ask before you leave rehab.

Julie's Journey

CATHETERS

Most pharmacies do not regularly carry catheters (especially small town pharmacies). There are so many different sizes and types that they would need a whole wall and, let's admit it, they would not make a great display! If you know exactly what you need — the style, size and brand — then your pharmacy will usually special order them in for you. Otherwise, the best advice is to order online. Find an online retailer that delivers free of charge — most do so within a day or two of ordering. You will likely get to try several different kinds while in rehab, so be sure you do before you get stuck on one brand. They vary in price and quality, so make sure you are happy with them before you are stuck with 99 more catheters that you don't really like!