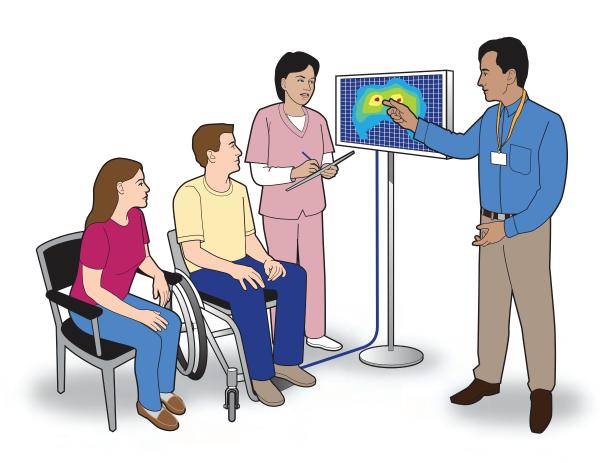
PRESSURE SORES

A guide for people with spinal cord injuries







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Funding support for this project was provided by the Ontario Neurotrauma Foundation.



Images of stage one, two, three and four pressure sores, suspected deep tissue injury, and unstageable pressure sore used with permission of the National Pressure Ulcer Advisory Panel, January 20, 2015.

Illustrations on page 22 used with permission from the Canadian Best Practice Guidelines for the Prevention and Management of Pressure Ulcers in People with Spinal Cord Injury: A Resource Handbook for Clinicians (2013).

This guide is also available as a free pdf download on SCI Ontario's website at www.sciontario.org/workshop-webcast/health-promotion and the Ontario Neurotrauma Foundation's website at onf.org/documents/preventing-and-treating-pressure-sores.

ABOUT THIS GUIDE

PRESSURE SORES (ALSO CALLED BEDSORES, DECUBITUS ULCERS OR PRESSURE ULCERS) CAN SERIOUSLY AFFECT PEOPLE WHO ARE LIVING WITH A SPINAL CORD INJURY. WE WROTE THIS GUIDE TO EXPLAIN:

- WHAT THEY ARE
- HOW TO PREVENT THEM
- HOW TO BEST TREAT THEM IF THEY OCCUR
- HOW TO TALK TO YOUR HEALTHCARE TEAM ABOUT YOUR SKIN HEALTH.

This guide is based on Canadian Best Practice Guidelines for the Prevention and Management of Pressure Ulcers in People with Spinal Cord Injury, A Resource Guide for Clinicians. 2013.

It can be hard to learn to manage your health when you have an SCI, especially if you can't find simple and clear explanations of what you can do to look after yourself. With this guide we are trying to increase access to research and education by describing the experts' recommendations in everyday language, and using pictures to explain important points.

Access to healthcare and related services, especially expertise in SCI, is limited for people living outside big cities like Toronto. We are using videoconference technology on the Ontario Telemedicine Network to share this information with you regardless of where you live or whether you are able to attend an event in person.

We have also worked with peers, or people with SCI, to review this document and make sure we haven't missed anything important. They have shared strategies learned through experience for preventing and managing pressure sores and for working with your healthcare team.

THE GIGANTIC COST OF A LITTLE SORE

At the time of my rehabilitation at Lyndhurst Centre in 2003, I was at my lowest low. I had no interest in doing anything. I barely had the energy to get out of bed. Besides my daily physio and occupational therapy, I took no part in other activities and events hosted by the hospital. Thus, I missed a lot of opportunities to learn about some of the most important knowledge on preventing secondary complications following a spinal cord injury.

Though I had heard the word "pressure sore," I never really understood what it was and how it forms. My only memory was having nurses intruding into my room in the middle of the night, turning me and positioning two pillows to elevate me. I found it annoying and often tossed the two pillows on the floor in protest.

After I was out of the hospital, the opportunity to be educated became even rarer. I gained 60 pounds upon discharge and the only advantage of having a full figure was having more cushioning on my bottom. Sitting on the wheelchair all day long did not bother me at all. I made no conscious effort to practise pressure relief.

About four years later, I lost a dramatic amount of weight. There was a lot of muscle atrophy on my bum. I noticed increasing discomfort when sitting on the chair full time. I felt like my sit bones were constantly poking me. I didn't know that I was using a foam cushion that was wearing out and desperately needed to be replaced.

One day, my mom found an abnormal area on my bum cheek, about the size of a loonie. Before long, the nurse diagnosed it as a pressure sore. That was the first time this condition made its proper introduction to me. I have since learned that this pressure sore was caused by a compromise in blood flow. Thinking back, I had done many things that were a big "no-no," such as sitting on a hard chair or lying down on a wooden floor for a prolonged period of time.

The healing process took about a year.

I had nurses coming to my home twice a week to change my dressings. Due to the limited amount of time I could sit up each day, my social life was affected and my school course load was reduced. Even when I was out, at the back of my mind I was constantly worried about putting pressure on my sore and worsening my condition. I was also advised to pause my swimming and other exercise routines. Because of these changes, my bowel movement was not ideal. I had to increase the use of laxatives. Also, the lack of exercise made me put on more weight, and my self-confidence and general health declined as a result.

Eventually, with the help of an occupational therapist, I got a Roho cushion, a Roho mattress, and a padded shower bench. I also learned to time myself in pressure relieving, lying down on my stomach during break time, using a special lotion to keep my skin moisturized and, most importantly, checking every vulnerable area on a regular basis.

The pressure sore left an ugly scar on my butt cheek. It's a forever reminder of how important it is to prevent secondary complications by equipping ourselves with knowledge and insights about our condition at all times.

NANCY XIA is the Community Resource and Education Assistant with Spinal Cord Injury Ontario in Toronto, Ontario.

MY EXPERIENCES WITH PRESSURE ULCERS AS A NURSE

My first true experience with pressure ulcers came about when I was hired to be a wound nurse at Parkwood Hospital in London, Ontario 22 years ago. I really was not prepared for what I saw and was dealing with. Most healthcare professionals receive very little education on pressure ulcers and I was one of those. I quickly learned how to assess and manage these very complex wounds.

My patients taught me many valuable lessons. I learned to listen to what they are telling me, as they understand and know their own bodies better than anyone. I also learned the hard way that patients need to be equal partners in healthcare. What impacted me the most was the human suffering caused by potentially preventable conditions. I have never forgotten it.

I went on to become a Nurse Practitioner and to complete my PhD. I studied how to prevent hospital-acquired heel pressure ulcers. I have devoted

my time help develop many Best Practice Guidelines on Pressure Ulcers with the Canadian Association of Wound Care, the Registered Nurse Association of Ontario and most recently The Ontario Neurotrauma Foundation and the Rick Hansen Institute.

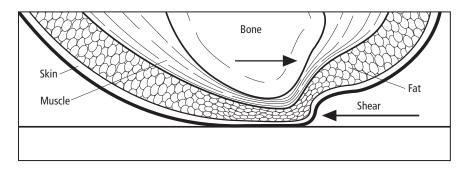
My current focus is on education of people with SCI and healthcare practitioners on best practices in pressure ulcer prevention and treatment. I hope one day to mentor more clinicians who understand how to best prevent and treat pressure ulcers.

KAREN CAMPBELL is Wound Project Manager, Lawson Research Institute at St. Joseph's Health Care in London, Ontario.

PART 1

WHAT ARE PRESSURE SORES?

Pressure sores are skin and tissue damage. They are caused by sitting or lying too long on one part of the body. They can also be caused by pressure combined with shear. Shear is when the skin moves one way and the tissue underneath moves the opposite way. This can happen when you slide down in bed or transfer your weight from one surface to another.



SHEAR CAUSING SKIN AND TISSUE DAMAGE

The deeper the sore is, the harder it is to treat. That's why it is so important to try to prevent them. You, and those who help with your care, should always watch for signs of pressure sores. Get them treated right away.

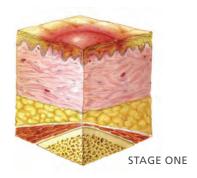
WHAT THEY LOOK LIKE

Doctors and nurses classify pressure sores in stages, based on the depth of the skin damage.

Stage 1

In a Stage 1 pressure sore, the skin is not broken but the area may be:

- painful or itchy
- pink or red on people with lighter skin, blue or purple on darker skin

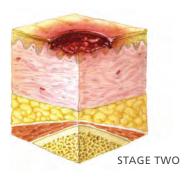


- when you press down on the skin, the darker colour does not go away or turn lighter (blanch) as it would on normal skin
- taut, shiny, or hardened
- warmer or cooler to the touch than the skin around it
- firmer or softer than the skin around it.

Stage 2

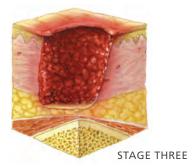
In Stage 2, there is a shallow, open, reddish-pink sore. Or, there may be a blister covering the sore, with clear fluid inside.

A Stage 2 pressure sore is different from other types of skin problems, such as tape burns, scrapes and cuts, or rashes caused by incontinence or moisture build-up.



Stage 3

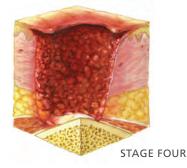
A Stage 3 pressure sore has gone quite deep, reaching into the fatty layer that lies under the skin. The sore may be covered with a scab or with dead tissue (called "slough"), which can be yellow, tan, grey, green, or brown.



Stage 4

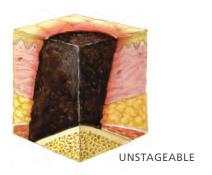
At Stage 4, the sore has reached right down to the bone, tendon, or muscle that lies under the skin. In places where there is not much fat, such as the ankle bones or the back of the head, the sore may not be deep, but it is still Stage 4 if it has gone right down to the bone.

Like in Stage 3, there may be scabs and dead skin which makes it hard to see how serious the damage is until the sore is cleaned.



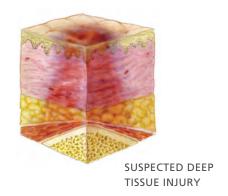
Unstageable

You can't see how deep an unstageable pressure sore is because it is covered with a scab or black or dead skin. Heel ulcers can be an example of unstageable sores.



Suspected deep tissue injury

Sometimes, there can be a very deep sore but the skin on top is not broken. The skin is purple or maroon, covering a blood-filled blister, with more dead tissue underneath. Like a Stage 1 sore, the skin may be painful, too soft or too firm, or too warm or too cool. This is called "suspected deep tissue injury."

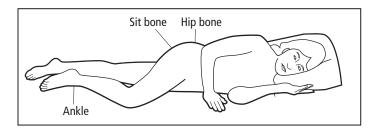


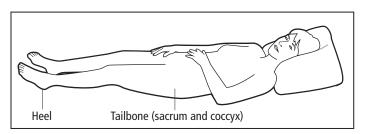
WHAT CAUSES PRESSURE SORES

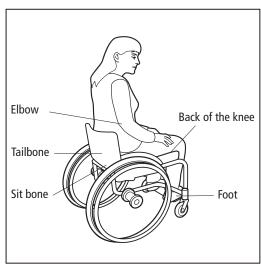
Sitting or lying in the same position for too long can cause a pressure sore. Medical devices like casts and tight-fitting clothing can cause them as well. Sliding over surfaces, or pulling your skin in opposite directions can also cause pressure sores. About 95 percent of people with spinal cord injury will have a pressure sore at some point in their lives.

The sores can develop where bony parts of your body make contact with surfaces you are sitting, leaning, or lying on, such as a bed or wheelchair. That is why it is so important to keep shifting position. Pressure sores can also occur in areas that are too moist.

This picture shows some common sites of pressure sores:







COMMON SITES OF PRESSURE SORES

Why people with spinal cord injury have a greater risk of getting pressure sores

PEOPLE WITH SPINAL CORD INJURY GO THROUGH PHYSICAL CHANGES THAT MAKE IT EASIER TO GET PRESSURE SORES AND HARDER TO TREAT THEM. HERE ARE SOME OF THE ADDITIONAL RISKS:

Changes to the body

COMPLETENESS OF THE SPINAL CORD INJURY: The less you are able to move (or the more body parts that are affected by your SCI), combined with how much feeling you have below your level of injury, will affect your risk of developing a pressure sore. Very active people with paraplegia are still at risk. The longer you have lived with your injury, the more likely it is you will develop pressure sores. People who have had a brain injury that affects their thinking are also at higher risk because they may forget to change position or eat properly.

MUSCLE ATROPHY: When sensation is lost and muscles are unused, they get smaller and weaker. That reduces the natural protective cushioning that muscles provide over bony areas.

BODY WEIGHT: Being overweight is common in people with spinal cord injury, and weight increases the risk of pressure sores. Very thin people, on the other hand, are also at risk. They have less cushioning between their bones and the surfaces they come into contact with. Also, some people may have poor nutrition, which can weaken skin tissues.

SIT BONES FLATTENING: The ischial tuberosities are the sit bones under the muscles of your bum. The shape of the sit bones gets flatter over time. For people with spinal cord injury who use a wheelchair, this area has the greatest risk of developing deep pressure sores.

LOSS OF CONNECTION BETWEEN NERVE AND SKIN: When the nerves are blocked from sending messages between the brain and the skin, the flow of

blood and oxygen decreases. The skin also makes less of a healthy connecting protein called collagen. These changes to the skin make it harder for pressure sores to heal.

SKIN THAT IS TOO DRY OR TOO MOIST: If a spinal cord injury causes problems with bowel and bladder control, it is harder to keep the area between the legs clean and dry. When there is a spinal cord injury above the T6 neurologic level, the body is unable to cool itself by sweating and can easily overheat. Dry skin is a risk factor for pressure sores.

LOWERED ABILITY TO FIGHT INFECTION: Spinal cord injury weakens the immune system, which helps us to fight off infection. That makes it easier for pressure sores to become infected.

AGING: Everyone's skin gets more fragile as we get older and our muscles and movement decreases.

OTHER HEALTH PROBLEMS: People with spinal cord injury who have other health problems, such as kidney disease, heart disease, other infections, poor nutrition, and iron-poor blood are at greater risk for pressure sores.

Other things that can increase the risk

LIFESTYLE AND PERSONAL CHOICES AS WELL AS QUALITY OF LIFE AND MENTAL HEALTH ALL PLAY A ROLE IN MAINTAINING HEALTHY SKIN. HERE'S HOW SOME OF THESE THINGS COULD INCREASE OR DECREASE THE RISK OF PRESSURE SORES:

PAIN: Chronic pain can be a big problem for people with spinal cord injury. Many people experience more than one type of pain—muscle pain and nerve pain, for example. If it is painful to shift and move your weight, you may not be doing it enough to avoid the risk of pressure sores. Ask your healthcare team for more help with pain management. They may know techniques for keeping pain under control while you move.

DEPRESSION: Depression is common in people with spinal cord injury, especially in the first few years after the injury. Chronic pain can also lead to depression. A person with depression may not be able to take care of themselves in the same way. Sadness that does not go away may mean clinical depression. Talk to your healthcare team. Treatment can involve speaking to a trained mental health professional, taking medication, or both.

COMMON SIGNS OF DEPRESSION

Sleep changes – you can't sleep, or you sleep too much

Appetite changes – you have lost your appetite or you can't stop eating

Trouble concentrating or doing things you normally find easy

Trouble controlling negative thoughts

Feeling hopeless and helpless

Feeling more irritable or aggressive than usual

Not taking care of yourself – e.g. you are drinking more alcohol than normal, taking risks, gambling out of control

Thinking life is not worth living (seek help immediately if this is the case)

NOT ENOUGH MONEY AND LACK OF ACCESS TO CARE AND EQUIPMENT:

Limited money is connected to many of the risks for pressure sores. People with spinal cord injury may have a fixed income, such as a disability pension. Having a disability is expensive. There are extra costs for things like medication and equipment. Bad or poorly maintained equipment can lead to pressure sores. Having enough Attendant Services hours of support and consistent support (someone who knows you and your body) makes a huge difference in preventing or managing pressure sores. If you don't have enough money for healthy food, your skin health can suffer. Not having enough money can isolate people and make it harder to reach out for help.

FINDING TIME FOR SKIN CARE: It takes someone with a spinal cord injury more time and energy to do everyday tasks, like getting dressed. If time and energy are limited some people may see it as a trade-off—taking added time for skin-checking and weight-shifting routines or just getting on with the day's activities. They may feel they simply don't have time for both. That's why it is so important for you and your healthcare team to come up with ways to make these routines part of your daily life. You need your own plan—one that fits your life and schedule.

ALCOHOL, RECREATIONAL DRUGS AND SMOKING: Alcohol, recreational drug use and smoking can affect your overall health in a negative way. They can also be addictive. Speak with your healthcare team if you need help with these habits.

A BREAK IN ROUTINE: Sometimes a life event, such as a death in the family or a sudden illness, causes a break in your daily routines. It helps to be aware of this danger so that you do not neglect checking your skin regularly.

QUESTIONS FOR MY HEALTHCARE TEAM

PREVENTING PRESSURE SORES

Preventing pressure sores involves:

- taking good care of your skin
- checking your skin often
- shifting or moving your weight regularly to prevent pressure from building up
- using the best possible equipment to minimize pressure
- choosing healthy foods and drinking enough fluid
- changing personal habits that put you at greater risk.



These are the guidelines that experts agree on.

SKIN CARE GUIDELINES			
USE	AVOID		
Warm water and liquid, pH-balanced cleanser	Perfumes and other ingredients that may bother your skin; bar soap		
Gentle wash cloth	Rubbing or scrubbing, which can damage blood vessels and tissue		
pH-balanced moisturizer, fragrance and alcohol free			
Keep skin clean and dry	Moisture, sweat and urine. If you are having problems with your bowel or bladder routine get help from a member of your healthcare team who is trained to deal with bowel and bladder issues.		

SKIN CHECKS

You should check your skin often—twice a day is good. Checking often means that you know what is normal for your skin. That helps you to spot changes.

If you need help checking your skin, try to have the same person help you all the time, so that they know what is normal for your skin too.

A skin check involves looking at and touching your skin, paying special attention to areas where pressure could build up.

HOW TO CHECK YOUR SKIN		
LOOK FOR:	 redness, bruising, or any change of colour changes in texture, such as rashes, dryness, or swelling cracks, scabs, and blisters 	
FEEL FOR:	 a difference in skin temperature from surrounding areas hardness or softness different from the surrounding skin. 	
USE A MIRROR OR PHONE	 use long-handled mirror to check parts of your skin you can't see ask someone else to hold the mirror Some people use their phones to check places on their skin they cannot see, by having someone take photos. 	

Do skin checks even more often:

- any time you are not moving as much as usual (e.g. if you are in bed during the day)
- if you have already identified a skin problem
- · when you are trying out new equipment
- when your lifestyle changes and you are sitting more often, or for longer stretches of time
- if your medical condition is getting worse.

PRESSURE MANAGEMENT

Pressure management is the term used for taking care of all of these things:

- redistributing or shifting your weight
- avoiding friction and shear
- eating healthy food and drinking enough liquids
- keeping your skin clean and dry.

The members of your healthcare team who are best equipped to help you with pressure management are the nurse, the occupational therapist and the physiotherapist. They will take a "24-hour approach" to assessing your pressure management needs. This means looking at all of the positions that your body will be in over the course of a 24-hour day, both waking and sleeping. These assessments should happen after you have your injury and be repeated regularly after that.

WHAT HAPPENS DURING AN ASSESSMENT

You, your family and your Attendants or Personal Support Workers know your body and your daily routine best. Your job is to communicate all that specific information about yourself to your healthcare team. Your healthcare team will start by getting to know you. They will ask questions about your injury, your goals, abilities, lifestyle, and personal preferences. They will need to know what you are able to do to help manage pressure on your own (for example, by shifting your weight).

The purpose of the assessment is to work with you to make sure you are comfortable in all positions over the course of your day and night. They will want to find out:

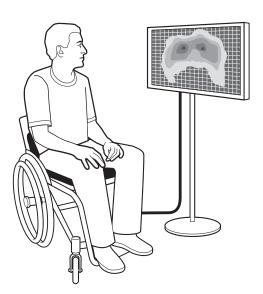
- what kind of help you will need to change positions
- what positions are best for you
- what kind of support surfaces are best for you
- what kind of equipment you need.

The therapists will want to observe you moving into and out of each of the positions you assume each day and on every surface (for instance, your bed, wheelchair, and commode). They will need to know the amount of time you spend in each position and on each surface. They will also want to watch you

performing typical tasks in each position.

They will inspect your skin before and after each move, by looking at it and touching it. This helps them see where the pressure areas are and how well your skin can tolerate these movements without them causing friction, shear, or injury.

The therapists may use a tool called *interface* pressure mapping. This is a flexible mat that measures the pressure between your body and its support surfaces. They may also take photos and video records to help them see how you are doing over time.



INTERFACE PRESSURE MAPPING

MAKING AN ACTION PLAN

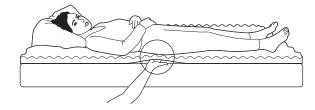
The therapist will use all of this information to work with you on making an action plan, which could include things like:

- getting you equipment or changing the equipment you are using
- planning an equipment trial to make sure it suits your needs
- helping you change the way you do some of your daily tasks to reduce pressure
- extra rehab to help you build up skills
- training for a person helping with your skin care routine
 Make sure your plan states times for follow-up and for the next complete assessment.

PREVENTING SORES WHILE LYING DOWN

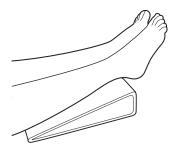
CHECK UNDER THE SIT BONES

 Make sure your mattress isn't wearing down in the places where your bones make contact



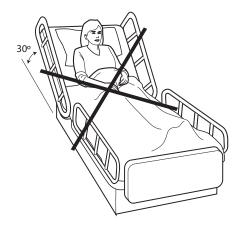
PROTECT YOUR HEELS

- Lift your heels up with a wedge cushion
- Or let them rest over the edge of the mattress



SIT UP IN A CHAIR, NOT IN BED

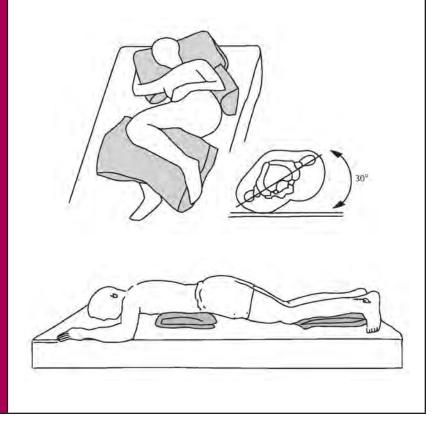
• Don't raise the head of the bed more than 30 degrees. Transfer to a chair with proper support for your bottom



PREVENTING SORES WHILE LYING DOWN

USE PILLOWS FOR SUPPORT ON YOUR SIDE AND STOMACH

- Take pressure off your knees and hips with cushions or pillows
- Make sure you feel comfortable

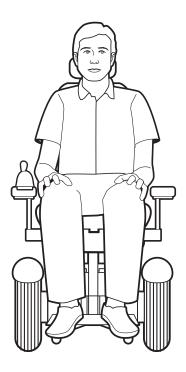


There are many kinds of support mattresses and seating surfaces. Your occupational therapist or physiotherapist can help you figure out what is best for you. If you need help finding a seating expert near you, or help finding funding, SCI Ontario's Regional Services Coordinators can help. Regional Service Coordinators assist people with spinal cord injuries in the transition from acute care through rehabilitation and back to the community. They are community resource experts who can help you access services where and when you need them. To learn more contact the local office close to you: sciontario.org/region or call 1-877-422-5644 extension 330.

PREVENTING SORES WHILE SITTING

MAINTAIN GOOD POSTURE

- Keep your posture in a neutral pelvic position
- Your sit bones should lie flat along the sitting surface
- Your weight should be supported along your bottom and thighs
- Check your posture throughout the day, especially when you start getting tired



USE COMMODES CAREFULLY

- Commodes often don't have enough surface area to distribute weight.
- If it takes a long time to finish your bowel routine, talk to your healthcare team about changing your commode or your position to one that redistributes pressure better

CHOOSING CLOTHING MATERIALS

CHOOSE THESE MATERIALS	AVOID THESE MATERIALS
Wick away moisture and don't build up too much heat.	
Breathable	
Soft and stretchy	Tight
Smooth	Thick seams and buttons, zippers, and pockets can all become pressure points. Watch out for buttons on the back pockets of jeans.
Shoes a size bigger than before your SCI	Tight shoes. Check your feet often when wearing shoes.

WEIGHT SHIFTING AND MOVEMENT

To be successful in preventing pressure sores, your routines for redistributing your weight should be built into in your daily activities so that it is impossible to forget them.

A pressure-relieving movement should last 1-2 minutes to be effective. Ideally you should redistribute your weight every 15 minutes. There are three ways that people with spinal cord injury and their caregivers relieve pressure on parts of the body:

FUNCTIONAL MOVEMENT: This means that you have enough control over your own movement to keep shifting your weight over the course of your daily activities, without even thinking about it too much. An example of this might be leaning forward to wash the dishes in the sink.

ACTIVE WEIGHT SHIFTS: This means that you have enough movement and strength in your upper body to shift your weight, following a planned schedule. This includes side-leaning, forward-leaning, and whole-body lifts.

WEIGHT SHIFTS WITH ASSISTANCE: This means that you use equipment to shift your weight. For instance, you or your caregiver might adjust the back of your wheelchair. Or, there might be a power tilt or recline function on the wheelchair that you or your caregiver can control.

COMMON WAYS TO SHIFT WEIGHT

LEANING TO THE SIDE

For people who have enough muscle control, this is a good way to get pressure off one buttock at a time.



LEANING FORWARD

This is fairly easy for many people to do and it is effective in relieving sitting pressure. It also looks quite normal to be in this position for two minutes, so you don't have to be self-conscious about it. You can support yourself if needed with a table in front of you.



LEG LIFT

Take pressure off the back of the knees by lifting each leg away from the wheelchair surface.



LYING DOWN	People who do not have enough muscle control to do active weight shifts should lie down regularly over the course of the day to take the weight off pressure points.	
STANDING AND WALKING	Some people are able to stand with support as part of their daily routine. This greatly reduces their risk of getting pressure sores. People who are able to walk with support should be careful to have shoes that fit well and do not damage skin.	
PUSH-UP	• •	

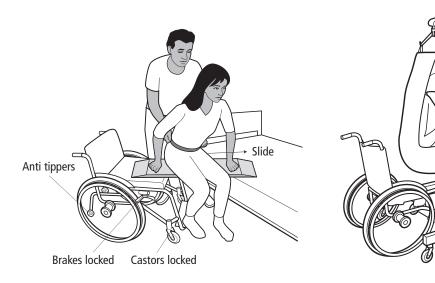
GROSS MOTOR SKILLS TRAINING

People with a spinal cord injury need to keep building strength, endurance, balance, and coordination. You need to watch carefully to see how moving around is affecting your skin. For example, if you are getting in and out of your wheelchair often, there is the risk of falls or bumps.

Gross motor skills training means that you work with an expert on your healthcare team to learn or re-learn how to use muscles to change position, relieve pressure, improve muscle tone, and increase blood circulation. If you use a manual wheelchair this training will help you learn how to move without putting too much strain on your arms.

Transitional movements means learning how to safely move from one position to another. You can use equipment such as sliders, bed rails, or trapeze bars to help you lift, rather than drag, your body. Rolling into or out of the lying down position, or moving from sitting to standing are examples of transitional movements.

Transfers are movements from one surface to another, such as from a bed to a wheelchair. The most common ways to do this are using a sliding board or a mechanical lift for people with higher spinal cord injuries.



TRANSFER USING SLIDING BOARD

TRANSFER USING MECHANICAL LIFT

Transfer tips

- Keep the distance between the two transfer surfaces as short as possible.
 For instance, placing your wheelchair parallel or at a slight angle to the transfer surface creates the smallest gap.
- Be aware of all parts of your body to prevent bumps, scrapes, and other damage to the skin.
- Lift your body away from the support surface—try not to drag it.
- Keep the space between the transfer surfaces free of obstacles such as arm and foot rests.
- It is easier if the surface you are transferring to is slightly lower than the one you are coming from.
- Choose smooth, low-friction, breathable materials for sheets, pajamas, mechanical lifts, and slings.
- Once you have finished your transfer, check your skin to make sure that it is not stretched or folded together.

Wheelchair training

Using a wheelchair puts you at high risk of pressure sores on your bottom. Research has shown that special training in using a wheelchair really improves people's skills and helps them to avoid problems such as pressure sores. Sometimes this training is available during rehabilitation right after your injury. Sometimes you can get training in your community.

There is a wheelchair skills training program at Dalhousie University in Halifax. They have published videos of wheelchair skills online available here: www. wheelchairskillsprogram.ca/eng/specific_skills.php.

There is also a series of online courses called SCI-U that has a course on Using a Manual Wheelchair available here: www.sci-u.ca/wheelchair/.

Regular exercise

Canada's Physical Activity Guidelines for Adults with Spinal Cord Injury recommend moderate or vigorous exercise and strength training. This chart shows a summary of the guidelines.

	HOW MUCH	HOW OFTEN
EXERCISE	The exercise should last at least 20 minutes.	You should have both exercise and strength training sessions twice a week.
STRENGTH	Strength training should include 3 sets of 8 to 10 repetitions for each major muscle group. It should also last 20 minutes.	
STRETCHING	People who use wheelchairs need to pay special attention to doing exercises for flexibility, because sitting for a long time can make muscles get tighter and shorter. Stretching exercises can be done alone or with help if needed.	

SCI Action Canada has published Physical Activity Guidelines for People with SCI in 11 different languages: sciactioncanada.ca/guidelines/.

The SCI Get Fit Toolkit shows the guidelines at a glance, and provides examples of activities and action plans: sciactioncanada.ca/guidelines/toolkit.

You can find strength training guides for people with paraplegia and quadriplegia here: sciactioncanada.ca/activehomes.

SCI Action Canada also has a free physical activity counseling service called Get in Motion: sciactioncanada.ca/get-in-motion.php or by phone at 1-844-882-4702.

SCI Action Canada and SCI-U have also created an online course on Physical Activity for people with SCI, available here: www.sci-u.ca/p207/.

NUTRITION AND FLUIDS

Poor nutrition and not getting enough fluids (dehydration) can both lead to pressure sores and prevent them from healing properly. People who are not able to eat and drink without help are at the greatest risk.

Weight loss is a warning sign for poor nutrition and pressure ulcer development. Gaining too much weight can also increase the risk.

A Dietitian who understands spinal cord injury can help you develop a nutrition plan that will ensure you have a healthy diet and get enough fluids. The plan should take into account:

- your level of injury and swallowing ability
- your dental health
- any food allergies you have
- your personal and cultural food preferences, and any religious restrictions
- your budget.

ELECTRICAL STIMULATION

Researchers have found that sending electrical pulses to the buttock area helps to improve circulation and prevent pressure sores. Ask your doctor or nurse about this preventive therapy.

QUESTIONS FOR MY HEALTHCARE TEAM

TREATING PRESSURE SORES

DEALING WITH CHALLENGES IN THE HEALTH CARE SYSTEM

Unfortunately pressure sores are very common. Research shows that 95 percent of people with a SCI will experience a pressure sore in their life time, so if you have one, you are not alone. Pressure sores are expensive, both for the health care system and for the people affected. The average cost of treating a pressure sore is about \$5000 per month for each person living in the community. Pressure sores can impact your ability to go to work or school, limit your social life and, in very bad cases, they can be deadly. For all these reasons it is essential that preventing and treating pressure sores be taken very seriously.

We are lucky to have a publicly funded healthcare system in Ontario. But our healthcare system is under strain. People with SCI experience this strain first hand. If you have a pressure sore you may have to wait several months for service. Our healthcare system simply does not have enough specialized outpatient rehabilitation clinics where you can access a team of experts trained in SCI. Another challenge you may face is securing enough support in the community when you return home after rehabilitation to continue your healing. Without the right support in place some people with an SCI resort to visiting hospital emergency departments to get help. This isn't good for your health, and it is not an efficient use of our healthcare system.

So what can you do? Resources like this guide can help you learn to spot the early signs of pressure sores. Sharing and discussing this guide can help you make sure your healthcare team is aware of the recommendations for preventing and treating pressure sores. Telephone and videoconferencing are good ways to link your healthcare team up with experts who live in other communities. These conferences can be used to discuss your treatment, to teach you about your care, to help you learn from other people with SCI, and to share best practices for treating you. You can also get involved

with networks like the Ontario SCI Solutions Alliance and help improve the healthcare system in Ontario for all people with an SCI.

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THE HEALTHCARE TEAM

Ideally, you and your family should be working with a team of experts trained in spinal cord injury who know how to prevent and treat pressure sores. When people with SCI have access to a team of experts like this research shows lower rates of pressure sores, and if people have a pressure sore, they heal faster. The members of the team should include:

- a physiatrist (a doctor with spinal cord injury training)
- a team member who specializes in wound care
- an occupational therapist who helps with seating and daily activities
- a physiotherapist who helps with movement and transfers
- a nurse who helps with medical care for your body
- a psychologist who helps with how you think and feel
- a social worker who helps with accessing the healthcare system and services, funding, and talking about how you think you feel
- a dietitian who helps with nutrition, hydration and meal planning.

Many Ontario communities do not have all of these experts in one place. You may need to travel to see a physiatrist, or to ask for a healthcare team that uses technology to include professionals in other communities.

Many people find the support of a peer who listens, shares their own experiences and provides practical information a helpful contribution to the professional services provided by their healthcare team. SCI Ontario's Peer Support Program connects people living with spinal cord injuries to Peer Support Volunteers in communities across Ontario. Trained Peer Support Volunteers are people with personal experience with an SCI and family members of people with injuries. These volunteers have "been there, done that" and are willing to help you and your family as you adjust to life with an SCI. To learn more you can contact SCI Ontario's Peer Support program at this email address: peerconnections@sciontario.org.

OPTIONS FOR TREATING PRESSURE SORES

Contact your doctor as soon as you see any sign of a pressure sore. They are much easier to treat in the early stages. Stay off the area completely until you have an assessment.

Your healthcare team will examine your sore and thoroughly check all of your skin. They will look at your medical history and your daily routines, to try to find out what has caused the sore. They will likely order diagnostic tests, such as blood tests and tissue cultures. If you have an infection, they will prescribe antibiotics.

There are many options for treating pressure sores, ranging from letting the area heal itself to performing surgery. The treatments that you and your healthcare team choose will depend on how serious the pressure sore has become. Your treatment choices are also affected by your general state of health, and whether you have an infection.

CHALLENGES YOU WILL FACE DURING TREATMENT

While you are being treated for a pressure sore, you will have to sit and lie in positions that keep the pressure off it at all times. Your lifestyle and level of independence may have to change for some time. If you will have to be in bed for a long time, ask a therapist on your healthcare team for an exercise routine you can do to help prevent your body from getting *deconditioned* or weak from lack of use.

Many experts do not support the use of full-time bed rest to treat pressure ulcers in people with spinal cord injury. If you have been asked to do this by your healthcare team, let them know about the Best Practice Guidelines for clinicians, and recommend they read the section on bed rest. You can find it online at this link: onf.org/system/attachments/168/original/Pressure_Ulcers_ Best_Practice_Guideline_Final_web4.pdf. Prolonged bed rest can seriously affect your health and strength, and may lead to depression. Watch for signs of depression and ask for help from your team.

While you are recovering, there is always the risk of developing a new sore in a different place, even if you have been using a special support surface. That makes it even more important to check all of your skin surfaces often.

Another challenge you will face is getting your support surfaces and equipment upgraded, if they helped to cause the sore. Wait times can be long for getting an assessment with an occupational or physiotherapist who has the right training. The costs of upgrading surfaces and equipment are also a challenge. Ask your healthcare team for advice on getting financial help.

NUTRITION WHILE YOU ARE HEALING

Calories

Having pressure ulcers increases your need for energy. Your body needs more when you are trying to heal a wound. Talk to a dietitian to figure out how many calories you need.

CHOOSE THESE	AVOID THESE
Nuts	White flour
Avocados	White sugar
Whole grain bread and pasta	Foods with a lot of added salt
Brown rice	Soft drinks
Legumes	
Potatoes	

Protein and amino acids

Meats, fish, lentils and beans, eggs and cheese all have lots of protein. Protein supplements are often helpful in healing pressure sores. Ask your Dietician if they would be right for you. Your healthcare team may also suggest that you supplement your diet with the amino acids arginine and glutamine, which help with pressure sore healing. Skim milk powder is a cheap protein supplement and can easily be added to lots of things.

Vitamins and minerals

Doctors may recommend vitamin and mineral supplements, such as vitamin C and zinc, for people with pressure sores. These supplements are only helpful for people who are low or deficient in them. Broccoli, red and green pepper, strawberries, orange, pineapple and papaya are all high in Vitamin C. Pumpkin seeds, red meat, yogurt, sesame seeds, oats and oysters are all high in zinc.

Vitamin A can help with healing in people who have other health problems such as diabetes. Sweet potato, kale, spinach and carrots are high in Vitamin A. Vitamin E can interfere with wound healing and should not be taken. Work with your doctor to figure out whether you need supplements.

Fluids

Your body needs enough fluids for healing and making new skin. Drinking fluids also helps your body fight infection because it helps get rid of waste.

There is an online course on Nutrition developed by SCI-U available at: www. sci-u.ca/nutrition-2/.

There is also a book online called "Eat Well, Live Well with SCI" that helps you use nutrition to address health problems relating to your SCI. There is a chapter on nutrition for pressure sores. You can find out more information about this book here: www.eatwelllivewellwithsci.com/.

Spinal Cord Injury Ontario, UHN Toronto Rehab Spinal Cord Rehabilitation Program and Joanne Smith, Holistic Nutritionist have made a book full of healthy recipes to help manage your SCI. You can print or download a copy of the recipe book here: www.sciontario.org/workshop-webcast/nutrition.

QUESTIONS FOR MY HEALTHCARE TEAM

WORKING WITH YOUR HEALTHCARE TEAM

Your relationship with your healthcare team is built on communication and trust. Your team are experts in prevention, diagnosis, treatment, and recovery. But you are the only one who has personal knowledge about your body and how it reacts and feels.

Here are some tips on communicating effectively with your team:

BEFORE YOU VISIT

To get the most out of your medical appointments it is good to prepare before each visit.

- Think about the questions you want to ask. Write them down and highlight the ones that are most important to you.
- Bring a print out from your Pharmacy of the medications you are taking.
- Know your medical history do you have other health issues, or have you had other treatments in the past?
- Know what you are allergic to.

DURING YOUR VISIT

Keep your visit focussed, but don't be afraid to ask questions. You may want to bring a close friend or relative who can help you speak up or make notes about the conversation to help you remember later.

Examples of questions you might want to ask

- What do you think caused my pressure sore?
- How is it going to be fixed?
- What should I do in the meantime?

- What can I do to help it heal?
- What should I do if my symptoms get worse?

Make sure your healthcare team listens to you. Keep in mind you may not be able to solve everything right away. When you are between appointments and trying to heal a pressure sore the experts say you should focus on nutrition.

RESOURCES FOR LOOKING AFTER YOUR HEALTH

CONNECTING WITH OTHER PEOPLE WHO HAVE SPINAL CORD INJURIES IS A GREAT WAY TO GET SUPPORT AND TIPS ON HOW TO PREVENT PRESSURE SORES AND OTHER PROBLEMS. BY SHARING INFORMATION WITH YOUR PEERS, YOU WILL GAIN INSIGHT INTO HOW TO MANAGE LIFE WITH YOUR SPINAL CORD INJURY. HERE ARE SOME USEFUL RESOURCES:

Spinal Cord Injury Ontario

SCI Ontario offers services for people with SCI and other physical disabilities across Ontario. We complement professional services provided in acute hospitals, rehabilitation centres and community-based health and social service agencies. Our website is www.sciontario.org/ or call 1-877-422-1112 x213 for more information.

Spinal Cord Essentials

UHN Toronto Rehab Spinal Cord Rehabilitation Program has made a series of handouts called Spinal Cord Essentials to help you manage spinal cord injury. The handouts cover information about your rehab stay, medical complications, self-care and financial resources. These handouts do not replace your healthcare team and are meant only as a written reference and general guidelines. They are available in English, French, Chinese and Farsi here: www. spinalcordessentials.ca.

SCI-U

SCI-U courses are designed to give you the information you need to live an active, healthy life after experiencing a spinal cord injury. They have been developed by people with spinal cord injury, working with researchers and healthcare professionals. You can access the SCI-U course on skin online here: www.sci-u.ca/p180/.

Ontario Spinal Cord Injury Solutions Alliance

The Ontario SCI Solutions Alliance is a coalition of organizations and people with spinal cord injuries trying to resolve systemic barriers (like long wait lists) to community integration and long-term health for Ontarians with SCI. The Alliance is supported by SCI Ontario and the Ontario Neurotrauma Foundation. Provincial meetings are held three times a year in Toronto, with conferencing abilities through phone and the Ontario Telemedicine Network. Want to know more or become involved? Contact them at alliance.sciontario. org/node/74.

Ontario Telemedicine Network

You can find webcasts about different health issues that you can watch online on the Ontario Telemedicine Network here: webcast.otn.ca/.

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SPINAL CORD INJURY ONTARIO is a non-profit organization with offices across Ontario. SCI Ontario assists people with spinal cord injuries and other physical disabilities to achieve independence, self-reliance and full community participation. Pressure sore prevention was identified by clients and staff as a priority topic for our learning series for people with SCI.

You can find out more about our Learning Centre here: www.sciontario.org/service/knowledge-enterprise

THE ONTARIO NEUROTRAUMA FOUNDATION (ONF) is a non-profit organization with a mission is to improve the quality of life of Ontarians living with Spinal Cord Injury (SCI). The ONF funds research and supports sharing research findings broadly among community, clinical and research partners. Pressure ulcers are one of the ONF's main priorities for research to improve healthcare services and the health of people with SCI. The ONF led the development of the clinical guide that provided the basis for this document.

Learn more about the ONF here: onf.org



