

Module 11 – SCI 101 for Researchers

Physical effects of SCI

The most visible effect of a spinal cord injury—and the focus of much of the SCI research done to date—is the loss of movement due to weakness or paralysis in muscles below the level of injury. But an SCI disrupts many aspects of physical function that have a profound impact on quality of life. Research that restores a fully functional and healthy body is important to people with SCIs and their families.

Here we will describe the impacts of some of the most common and serious physical effects of an SCI that may be less obvious than motor function, but that increase mortality and reduce quality of life.

Sensation

Some people with spinal cord injuries lose some or all sensation below their level of injury. Loss of sensation can happen to anyone with an SCI, regardless of the level of injury. It is possible to have a loss of sensation in parts of the body that a person with an SCI is still able to move. It's a safety issue, because people who do not have sensation may not feel touch, or know that a hot or sharp object is touching them, or be able to detect injuries to themselves.

Josh Forbes – I actually fell and broke my femur, I've broken toes, I've gotten burned, as I couldn't feel properly.

Pain

Many people with spinal cord injury experience one or more types of chronic pain—even, for some people, in parts of the body that no longer have normal sensation. Chronic pain, its treatments and their side effects can interfere with activities of daily life, sleep, mood, and overall quality of life.

Type	Where	Causes or triggers	Complications
Neuropathic pain	Any part of the body at or below the level of SCI	<ul style="list-style-type: none"> • Spontaneous • Evoked by stimuli • Triggered by spasm 	<ul style="list-style-type: none"> • Resistant to standard treatment
Musculoskeletal pain	Muscles and joints	<ul style="list-style-type: none"> • Overuse/repetitive strain 	<ul style="list-style-type: none"> • Resting the injury may restrict mobility all together
Visceral pain	Abdomen, chest, and pelvis	<ul style="list-style-type: none"> • Inflammation, pressure, or injury to internal organ(s) 	<ul style="list-style-type: none"> • Can trigger neuropathic pain
Painful edema	Extremities	<ul style="list-style-type: none"> • Lack of movement 	<ul style="list-style-type: none"> • Can lead to skin wounds

As just one example, neuropathic pain is common in people with all levels of spinal cord injuries. They may feel neuropathic pain in the areas of the body that are supplied by nerves at the level of injury, or throughout the body below the level of injury.

This nerve-related pain is often described as sharp, stabbing, tingling, or burning pain. It can be severe and can interfere with everyday activities, sleep, mood, and overall quality of life. It can be spontaneous, or evoked by stimuli such as touch, or cold. And it often does not respond to standard treatments.

Trevor – One of the challenges I face is chronic neuropathic pain. People may not realize it, but I have this burning sensation in my body all the time. I'm probably more withdrawn when I'm in pain.

Musculoskeletal pain also is common due to overuse of muscles and joints, especially in people who use manual wheelchairs. Overuse injuries are difficult to treat because wheelchair users cannot avoid repetitive movements.

Spasms

People with spinal cord injury may have involuntary movements, or spasms, anywhere in the body.

Spasms can be triggered and sustained by touch, movement, body position, temperature, or illness. They may interfere with activities such as eating, getting dressed, or transferring from one surface to another. They can be painful themselves, and may also trigger neuropathic pain. Spasms are also a safety issue, as they can cause falls or injuries.

However, some people are able to use spasms to their advantage, for instance, to assist with transfers.

Bowel and Bladder Dysfunction

Most people with spinal cord injury experience a complete or partial loss of their ability to control when their bowels or bladder will empty.

A person with a spinal cord injury may not be able to feel that their bowel or bladder is full, leading to incontinence. Their brain also may not be able to stimulate their bowel and bladder muscles to empty, leading to constipation or urinary retention.

People with spinal cord injury who have neurogenic bladder or bowel use devices and special routines to empty their bowels and bladder. These routines may require assistance, and can be time-consuming and embarrassing.

Effective bladder and bowel management are crucial to avoiding other serious health problems, such as urinary tract infections and autonomic dysreflexia (a sudden and life-threatening rise in blood pressure).

Bowel and bladder issues have profound effects on the daily life of someone with a spinal cord injury.

Sasha Rabchevsky – Your whole day, life is scheduled around whether and how you will go to the bathroom. At the workplace it's kind of difficult sometimes if I have to, if I do really feel that I have to do a bowel program or something like that I don't feel comfortable doing it at work, I have to go home and do that kind of thing, but I think many people even able bodied people sometimes feel that. But for me it's for practicality purposes.

Claudia Garofalo – And then on top of that, is, like, timing when you do decide you have to go somewhere, if your bathroom needs are met, because as someone with paralysis that's a big deal for us. Those two things I guess are just always lurking in the back of my mind, and it's aggravating.

Sexual Dysfunction

Most people with spinal cord injury experience some degree of sexual dysfunction, such as:

- Difficulty or inability to have an erection, or lack of vaginal lubrication in response to arousal in the brain and/or physical stimulation, depending on the level of injury.
- Inability to orgasm, depending on the level of injury.
- Problems with mobility, positioning, and/or spasticity.
- Risks of injury or complications such as autonomic dysreflexia during sex.

Sexual dysfunction can lead to a loss of intimacy and contribute to loss of confidence or self-esteem, depression, and other psychosocial effects.

Jerrod Kerr – In the hospital it's like there's a whole realm of the mechanics behind it that I was educated on before I left the hospital but not so much the emotional side of it, how it's affecting you emotionally, like the depression that comes with not being able to do something,

no matter what it is, that you used to be able to do--let alone something that I think our identities are tied very strongly to. So there's that whole realm of the initial part, the first 3-6 months on the physical aspects, and then a year and a half to the mental or the emotional aspects just to get to the level of competency in dealing with this new reality.

Cody Unser – I became paralyzed when I was 12. So my sort of sexual perspective is a little different because I didn't know anything prior. Personally for me, being paralyzed, uh, or having some sort of medical condition that's chronic, uh, it kind of opens up the door for more intimate moments with somebody because from the get go, I have to be really honest about bladder and bowel control, which, you know, uh, kind of goes out the window during sexual activity. There's no way around it. There is absolutely--I'm in that moment, right, and I have to sit there with that, those feelings and that's something that a lot of women, you know, and men too, um, deal with. The other issue is, definitely attitudes and lack of education because a lot of medical professionals don't get this kind of training in medical school and that kind of leads to consequences, um, especially like false assumptions, like, um, a lot of OB GYNs don't think I'm sexually active. I don't know if it's because they think it might be too hard or physically difficult for somebody to have sex with me, or somebody's not interested in me because I am paralyzed. Um, but there are so many negative stereotypes and microaggressions that we deal with. I really hope people do more research around that topic.

Pressure injuries

People with spinal cord injury are at very high risk of developing pressure injuries, also called pressure ulcers or pressure sores.

People who cannot feel pressure or pulling may not know that damage is happening. Pressure injuries can lead to serious and even fatal infection. A single pressure sore can disrupt someone's life for months.

Gary – Having a pressure sore causes problems if you don't attack it in the early stages, because what happens is if you have a stage three pressure sore, and you're unable to relieve the pressure on it, then you're probably gonna have to stay in the bed. If you're in the bed, you can't do anything all day. You can't do your normal routine. So, it just throws everything off when you have to stay in the bed and it's all because of a pressure sore.

Trevor – And if I'm stuck in bed, then I'm not up and about. I'm not getting out, and I can become depressed because I'm not active.

Breathing

Almost everyone with a cervical or high thoracic spinal cord injury will have some difficulty with breathing because of weakness or paralysis of their chest or abdominal muscles.

Some individuals with high cervical complete injuries may require a ventilator.

Garret Frey – So I have a bedside ventilator that I use at night time, uh, that it's very nice to have two different ventilators. One's on my wheelchair and one's on my bedside. I myself, I have a suction machine that I suction a few times a day. It just depends on, um, different, uh,

mucus and times of year, just sometimes in the winter., the thing that I get worried about is, uh, changing my trach or my circuit that can come apart. And that does happen, but yes, to teach your caregivers or people that are around you, your family, your friends, uh, how to help you with everything that you need.

People with an SCI also may have difficulty coughing, which is necessary to clear the airways. They may have more difficulty recovering from a cold. They are more likely to develop pneumonia or other life-threatening breathing problems.

Infections

In fact, sepsis and other complications of infection are among the leading causes of death for people with spinal cord injury.

Problems with Joints, Muscles, and Bones

People with spinal cord injury may develop problems with their muscles or bones because of lack of movement or weight-bearing activities.

People with spinal cord injury often have osteoporosis and are at high risk of fractures from falls, transfers, or other everyday activities.

Cody Unser – I have osteoporosis because I haven't been standing and bearing weight all that much since I was 12. And so I can't get too creative in the bedroom or I'll break a bone, just things like that, you know? Um, very specific things, uh, that I think need to be kind of researched.

Many people with an SCI experience muscle atrophy, which in turn can increase the risk of metabolic disorders. Muscle atrophy or weakness also changes the body's appearance—for instance “quad belly” or “para belly” from weakness in the abdominal muscles.

These changes in physical appearance may affect self-esteem.

Cody Unser – I have what's called a ‘para gut’ and that's a body image issue that I deal with even now at 35 years old. So, you know, when somebody becomes paralyzed, no matter at what age, I mean, it's really hard to navigate the world and especially like everybody wants to be loved and liked and, um, you know, held. Um, so it's, it definitely does sort of affect your confidence and trying to get that back. It's always like a yoyo, you know, it's, it's never settled.

Other Serious Complications

People with spinal cord injury may have problems regulating blood pressure and body temperature, some of which can be life-threatening.

Type of dysregulation	Description	Cause or trigger	Complications
Orthostatic hypotension	Sudden drop in blood pressure	Change in position	Fainting Nausea
Autonomic dysreflexia	Extreme rise in blood pressure	Illness or stress on the body	Life-threatening

Thermoregulation	Difficulty keeping warm or staying cool	External temperature	Heat stroke Hypothermia
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As one example, a person with a spinal cord injury at the T6 level or above may experience very high blood pressure called “autonomic dysreflexia.” This sudden rise in blood pressure can be life-threatening.

It usually happens when something is bothering the body. Examples of triggers include bladder distension, bladder or kidney stones, UTI, pressure sores, an ingrown toenail, fractures, and sexual intercourse.

Aging

There are many more physical effects of an SCI beyond the ones we’ve discussed here. It’s important to remember that different people experience different physical effects, and even those who experience the same physical effects may experience them with different intensity.

In addition, the physical effects of an SCI can change over time, with some improving following the acute phase of injury, and others worsening with age.

It can be hard for some people to differentiate between worsening complications of an SCI and regular effects of aging.

Claudia Garofalo – SCI is something that you live with for the rest of your life. And there’s all different stages that a person and a person’s body goes through with SCI. And I guess I’m now at a new stage of experiencing the long-term ramifications of being someone with a spinal cord injury. I feel like my body is dying on me from the inside out. And um I don’t know if that’s true, I haven’t really talked to any medical professionals about it because I don’t want the answer but I’ve over over the last year especially I have noticed a lot of changes, subtle changes, changes that are happening slowly but they’re definitely happening and that scares me. I’m 65 and I come from good healthy stock my body shouldn’t be doing this except that I am a person living with paralysis.

Next, we’ll talk about psychological and social effects of an SCI that also affect quality of life.