



## Incomplete Spinal Cord Injuries: Down the Road

*This is the second of two brochures about incomplete spinal cord injuries. The first, [Incomplete Spinal Cord Injuries: The Early Days](#), discusses some of the issues people with incomplete injuries face soon after injury – especially during rehabilitation. This brochure discusses issues that may become important later on....*

Having a spinal cord injury that is incomplete often means less paralysis, more sensation, and maybe an easier time managing your bowels and bladder. It can also mean more sexual function, and it often means that getting around, taking care of yourself, and doing things will be easier than if your injury had been a complete one. However, having an incomplete spinal cord injury is not a “walk in the park.”

### Four Kinds of Problems

Our research turned up four main areas where people with incomplete spinal cord injuries may have problems or frustrations:

- The “wait and see” mode
- Pain
- Fatigue and weakness
- Emotional issues

### Wait and See

We described the emotional stress related to “wait and see” how much muscle recovery might happen in another brochure: [Incomplete Spinal Cord Injuries: The Early Days](#). You might want to read through that one again. However, there is also some medical “waiting and seeing” going on, too.

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For example, people with incomplete spinal cord injuries often leave the hospital with spinal fractures that are still healing and being followed by their doctors. In fact, in one study, 20% of the people we surveyed were discharged from the hospital before their spinal fracture was fully healed. Many were still wearing back or neck braces, or had been told by their doctors to limit their range of movement or avoid specific activities – like lifting, twisting, or stretching. What does this mean? Often, even though you may feel you are physically able to do an activity independently, you may still need short-term help. Examples could be dressing, getting up from the floor after a fall, climbing stairs, and driving.

Getting the help you need for these activities may take some creativity – especially if you don't have an insurance policy that will pay for extra help and care in the home. Friends, volunteers, church members, or college students are possible options.

## Pain

Pain can sometimes be a problem for people who have incomplete injuries. It's kind of a double whammy: the good news is that having more sensation is always a good thing; the bad news is that having more sensation will also give you the ability to feel pain – and pain is rarely any fun.

In our study, 25% of the people with incomplete injuries complained of pain in their backs, necks, or in other joints. In another study, as many as 40% of people with incomplete injuries complained of pain. That was twice the amount of people with complete paraplegia who had pain. Chronic pain can be incredibly annoying – and sometimes disabling. However – and, perhaps fortunately – it's new or changing pains that you need to be particularly aware of. It's these kinds of pain, and not typically the ongoing, unchanging chronic pains, that usually tell you that something is amiss.

Strangely, not enough pain can be a problem too. Although the most frequent scenario is to have more feeling than movement, it is possible for the opposite to happen, too. It's possible for muscle function to return, but not sensation. It's also possible for the deep sensation to be damaged, without you being aware of it. When sensation within a joint is impaired and you cannot feel normal pain in that joint, it's referred to as a Charcot joint. If you have a Charcot joint – especially if the muscles around that joint are working pretty well – you need to be pretty careful.

That's because without pain as a warning signal, it's possible to be doing transfers, exercising, or even up and walking, and damaging a shoulder, hip, or knee joint without even knowing it. When should you worry? If you're able to use an arm or a leg pretty well, but know that it doesn't feel quite right, review this with your doctor. He or she may want to monitor you closely with x-rays and other tests.

## Fatigue and Weakness

People with incomplete injuries who are able to walk complain of fatigue significantly more often than those with incomplete injuries who are wheelchair users. In fact, half of all walkers complain of fatigue. It's also noteworthy that more than twice as many people with incomplete injuries – 19% – complained of neurologic deterioration during the first year after their injury. Even more had the complaint in following years. They reported things like strength loss, changes in sensation, and decreasing bladder function. However, subtle changes are easier to notice when the injury is incomplete and there's remaining muscle function and sensation. And, it's easy to confuse fatigue, pain, or illness with actual changes in your spinal cord injury.

The bottom line: if you think you see a change, don't ignore it. Make a list of specific changes and things you can't do that you once could, and share it with your doctors or therapists. Ask them to take baseline measurements of your strength or sensation so they can record your status at one point in time to compare it with a later point in time to see if there have been real changes.

And – regarding fatigue: take it seriously. New research is suggesting that fatigue is a major issue for people with all kinds of spinal cord injuries the longer they have been injured. It won't go away on its own, and it's only likely to get worse, unless you do something about it – a change in your schedule, routine, or even the equipment you use might help.

## Emotional Issues

Here's what we found in one study we did. Included in these numbers are people with all kinds of incomplete injuries; some had enough muscle function to walk; others did not:

- More people with incomplete injuries (29%) complained of having money problems than people with complete paraplegia and tetraplegia (25%) during the first year. By five years, even more of them (35%) complain of financial problems. This could be because they have a harder time getting disability benefits, unemployment, Medicaid, etc.
- More people with incomplete spinal cord injuries reported alcohol problems: at one year, 6%; at five years, 14%. Though these percentages are small, they're almost twice as high as among people with complete injuries.
- 10% reported feelings of depression.
- Other problems were rarer, but are worth watching out for: increased alcohol use by the *spouse*, new behavioral problems appearing in the individual's children, and sexual difficulties.

## The Good News

Don't overlook the good news! In our research, we found that, despite the financial problems some people with incomplete injuries had, as a group, they had a better employment track record than their complete counterparts. They were also more involved in volunteer work and other productive activities. They reported their quality of life to be a bit higher than those with complete injuries and they had better scores on life satisfaction, well-being, and stress tests. And, they seemed to have done better than people with complete injuries when it came to getting back into their communities and resuming their old activities – things that their non-disabled peers were doing.

People with incomplete injuries also complained of fewer unmet needs. Fewer complained of not having a spouse, or children to raise, and only 3% — nine times less than the complete injuries — complained of having troubles making friends and socializing.

## Getting Some Perspective

In some ways, having an incomplete injury may be easier than having a complete injury; but, in many ways, it's still pretty darn hard. However, regardless of what data and statistics say, in every way, an incomplete spinal cord injury is your own, unique, individual experience. Certainly, don't expect yourself to have problems just because other people have them – but at the same time, don't assume the risks don't apply to you. Keep these things in mind:

- You need to have good – and regular – medical check ups.
- Don't assume your spinal cord injury is a thing of the past.
- Expect that things will get harder if you have an illness, an operation, a major life stress – and as you get older.
- Plan ahead and have help and equipment lined up. If you've been injured a number of years, be aware that there have been many changes in equipment and technology. There may be things available now to make your life easier that weren't available years ago.
- Don't ever feel you can't ask for help.
- Be in touch with your body. Don't obsess on minor changes and fluctuations, but don't ignore them either. Do you think you might be changing? List out specific and concrete examples and present them to doctors or therapists who are experienced in spinal cord injury treatment.

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