

# Incomplete Spinal Cord Injuries: The Early Days

*What's all the confusion about "complete" and "incomplete?" Complete usually means "total" or "whole," while incomplete usually means unfinished," or" not yet perfect." Although there aren't many situations where we would like to hear ourselves described as "incomplete," spinal cord injury may be one of them. Indeed when it comes to nerve injuries and muscle paralysis, most everyone thinks that a partial paralysis or an incomplete injury is better than a complete injury or total paralysis. Does this mean that an incomplete injury is a good injury? It depends on how you look at it.*

In the world of spinal cord injury, incomplete tells us a lot and very little at the same time. It tells us that the person does not have total paralysis or loss of sensation, that his or her spinal cord was not totally damaged or disrupted. But that's all it tells us. Incomplete injuries run the gamut:

- They can be so mild that they cause almost no muscle weakness or visible signs that a spinal cord injury ever even happened.
- They can be so severe that they leave the individual looking and feeling not very different from someone who has a complete injury – except, perhaps, for some areas of preserved sensation.
- Typically, they fall somewhere in between.

## The Facts:

There's almost always hope of recovering at least some function after a spinal cord injury. But is there more hope after an incomplete injury? Perhaps – at least early on. Here's what we know:

- Spinal cord injuries that did not cause total paralysis have the best chances of additional recovery. In a large study of all new spinal cord injuries occurring in the state of Colorado, only one in seven of those who had complete paralysis immediately after injury got a significant amount of movement back. But, of those who still had some movement in their legs immediately after injury, three out of four got significantly better.
- People whose spinal cord injuries did cause complete paralysis may still have a good chance of muscle recovery if they have sensation in the lower part of their body just after injury. About 2/3 of those with neck injuries who can feel the sharpness of a pin-stick in their legs eventually get enough muscle strength to be able to walk. Of those with neck injuries who can only feel light touch, about 1 in 8 may eventually walk.

- The sooner that muscles start working again after a spinal cord injury, the better the chances are of additional recovery – especially for walking. However, when muscles come back much later – after the first several weeks – researchers have reported that they are more likely to be in the arms than in the legs.

## Will I walk again?

How long do these better odds of recovery go on? How long should a person with an incomplete injury – or even one with a complete injury for that matter – continue to hope for recovery?

There's no easy answer. Certainly, by two or three years after the injury, the chances of paralyzed muscles starting to work again on their own are pretty small. What about one month, two months, or six months after the injury? It's a little harder to predict, but there are two rules of thumb:

- As long as you're seeing some improvement and additional muscles recovering function, your chances of seeing more improvement are better.
- The longer you go without seeing improvement, the lower the odds are of improvement just starting to happen on its own.

## Dilemmas:

So, at the same time that an incomplete injury is a good thing, it does create some dilemmas:

- How do you deal with the fact that no one can give you a really good prediction of what to expect a year or two into the future? As any spinal cord injury can be life-changing, you need to plan for the future. Should you go ahead and modify your house, or should you wait? Should you buy a van, or hang on to that four door sedan with the stick shift a little longer?
- How long should you let your life stay on hold while you watch to see what kind of recovery you'll get? Do you quit your job to focus on therapy for the next six months or year? Do you postpone a big trip, a graduation, a move – on the chance it might be easier later on – or do you go ahead and do it now?

## Possible Guidelines

There aren't really any easy answers. And, unfortunately, people with incomplete injuries may face other, more immediate challenges, too:

- For some, the length of inpatient hospitalization may be shorter, while more time may be spent in outpatient therapy. This is good – it gets you home faster. But, at the same time, it sometimes causes you to miss out on inpatient programs, classes, and even chances to interact with other people with spinal cord injuries and professionals whose experiences you might benefit from.
- Compared with people with complete spinal cord injuries, there are – and probably always will be – fewer people with injuries just like yours who are going through the same things you are.
- You may feel neglected or overlooked. Often rehab, and even many community programs, as well as building adaptations and specialized equipment, seem as if they're designed for the person with the complete injury. This can be a particular problem if, for example, your incomplete injury affects your mobility but doesn't require you to use a wheelchair all of the time; or, if your legs work pretty well but your arms are not too cooperative.
- Even more concerning, benefit programs may be harder to qualify for. The doctor charges, hospital bills, and therapy sessions can be just as expensive as when your injury is a complete one, but because your condition may be changing, you may not qualify immediately for benefits like Social Security, Medicaid, or vocational rehabilitation. Why? Programs for people with disabilities have limited resources and tight purse strings, so they often prefer to spend their money on people who they think are the most likely to be permanently disabled. When there is an incomplete injury, they may want to take a wait and see approach. That waiting and seeing can go on for months – or even longer.

## Perhaps Worst of All...

All these things are bad enough, but there's a double whammy: You may have days when you feel – there may even be days when it seems that others are actually telling you — that you have no right to feel sad, depressed, or frustrated. No matter how bad or overwhelming all of the things we just described may be, no one allows you to forget that “It could have been worse.” It may be your own conscience that tells you, or it may be a well-meaning visitor: “Just look around you. See all the people who have worse problems than yours...”

This doesn't help a whole lot. It's like being caught between a rock and a hard place. When you're feeling low, you're reminded how much worse it could have been... When you're feeling up and ready to move on with your life, you're told to be patient and wait and see.... If someone thinks you're spending too long waiting and seeing, you're told to "get on with it." If it's any consolation, you'd be surprised at how much even people with complete injuries hear the same things and put up with the same feelings. It seems there's always someone who's willing to point out that "It could have been worse."

## What Can You Do?

Know that you're allowed to feel the way you feel. You don't need to feel grateful that your life isn't even more overwhelming or more topsy-turvy than it already is. You don't need to feel guilty for thinking about – and missing – what's been lost.

At the same time, know – believe – that things will get better. Whether you get a lot of recovery or just a tiny bit more, it is going to get easier. Try to find a balance between "wait and see" and "get on with it." You don't want to try and conquer the world tomorrow, yet you can't leave your whole life on hold either. Check with others around you – your therapists, friends, family, etc – to get a feel for what they think is a good balance.

Realize that no matter how much recovery you have, your life will be different, in some way. There will be problems you'll want to take steps to avoid; there will be adjustments that will be required. With the right planning, different doesn't need to mean worse.

## Getting Some Perspective

Remember: Most people with spinal cord injuries – whether complete or incomplete – do cope. In fact, most are satisfied with their lives. In research done several years ago, even people with very high tetraplegia who depended on mechanical ventilators were happy. More than 90% were glad to be alive; more than 85% said their quality of life was at least average – many said it was excellent! It's very likely that you will feel this way, too.

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