

EXPECTED OUTCOMES – WHAT YOU SHOULD KNOW

A GUIDE FOR PEOPLE WITH C1-3 SPINAL CORD INJURY

This guide describes outcomes of your spinal cord injury (SCI):

A COMPLETE C1-3 SCI:

Injury between the first and third cervical spinal cord segments with complete paralysis below the level of injury.

The purpose of this guide is to describe what can reasonably be expected for daily functions.

This information can help you and those who care about you to understand the present, and plan for the future. It explains important information that can be useful to you, such as:-

- What can a person with SCI expect to do one year after injury?
- What help is likely to be needed with daily life tasks at home, at work and in the community?
- What equipment can help make a person with SCI more independent?

A spinal cord injury (SCI) is damage to the spinal cord resulting in a loss of movement or feeling. The spinal cord is a bundle of nerves that runs through the bones making up the spinal column. The spinal cord does not have to be totally cut or torn for a loss of functioning to occur. On the other hand, a person can “break their back or neck”, and not have a spinal cord injury if only the bones around the spinal cord (vertebrae) were damaged and the spinal cord was not affected. In these situations, the individual may not have paralysis after the bones are stabilised.

Rings of bone called vertebra surround the spinal cord. These “back bones” make up the spinal column. The higher the injury to the spinal cord, the more the individual usually experiences activity limitations. The vertebrae in the neck are called cervical vertebrae. The top vertebra is C1; the next is C2, and so on. Cervical spinal cord injuries usually cause loss of function in both arms and legs. This is called tetraplegia, sometimes referred to as quadriplegia.

What Are “Outcomes”?

When we talk about “outcomes” after SCI, we mean many things:-

- Movement/sensory recovery.
- Ability to perform common daily functions.
- Social life in the community.
- Overall quality of life.

An outcome is a change that happens to you because of an event, such as a spinal cord injury. These can be described in the following ways:-

- **Impairment outcomes** – health problems or illnesses.
- **Activity outcomes** – basic tasks you do for self-care (breathing, eating, dressing and moving around). These activities can be done with or without help from special medical equipment or another person.
- **Participation outcomes** – ways you connect with others in the community like being a friend, partner, parent, student, employee or volunteer.

- **Life satisfaction outcomes** – how you see yourself and your quality of life.

This guide focuses mostly on **activity outcomes**. The other outcomes described above are very different for each person. You should think about ways to pursue your own interests following your injury. Ways you can participate may include:-

- Communicating with other people (in person, by telephone, or by email).
- Altering and adapting environment and lifestyle to allow you to do your job, go to school, and have fun.
- Discussing with and asking your friends, family and others for ideas and suggestions.
- Planning to stay healthy, active, and satisfied.
- Going back to work, school and school continuing your education and pursuing activities and hobbies.

What Influences Outcomes after SCI?

A spinal cord injury changes many things. Those changes depend on many factors. Each part of the bundle of nerves called the spinal cord controls different parts of the body.

By now, you may know what “C1-3” means, but family and friends may find some explanation helpful. The spine has four sections: -

- Cervical (C)
- Thoracic (T)
- Lumbar (L)
- Sacral (S)

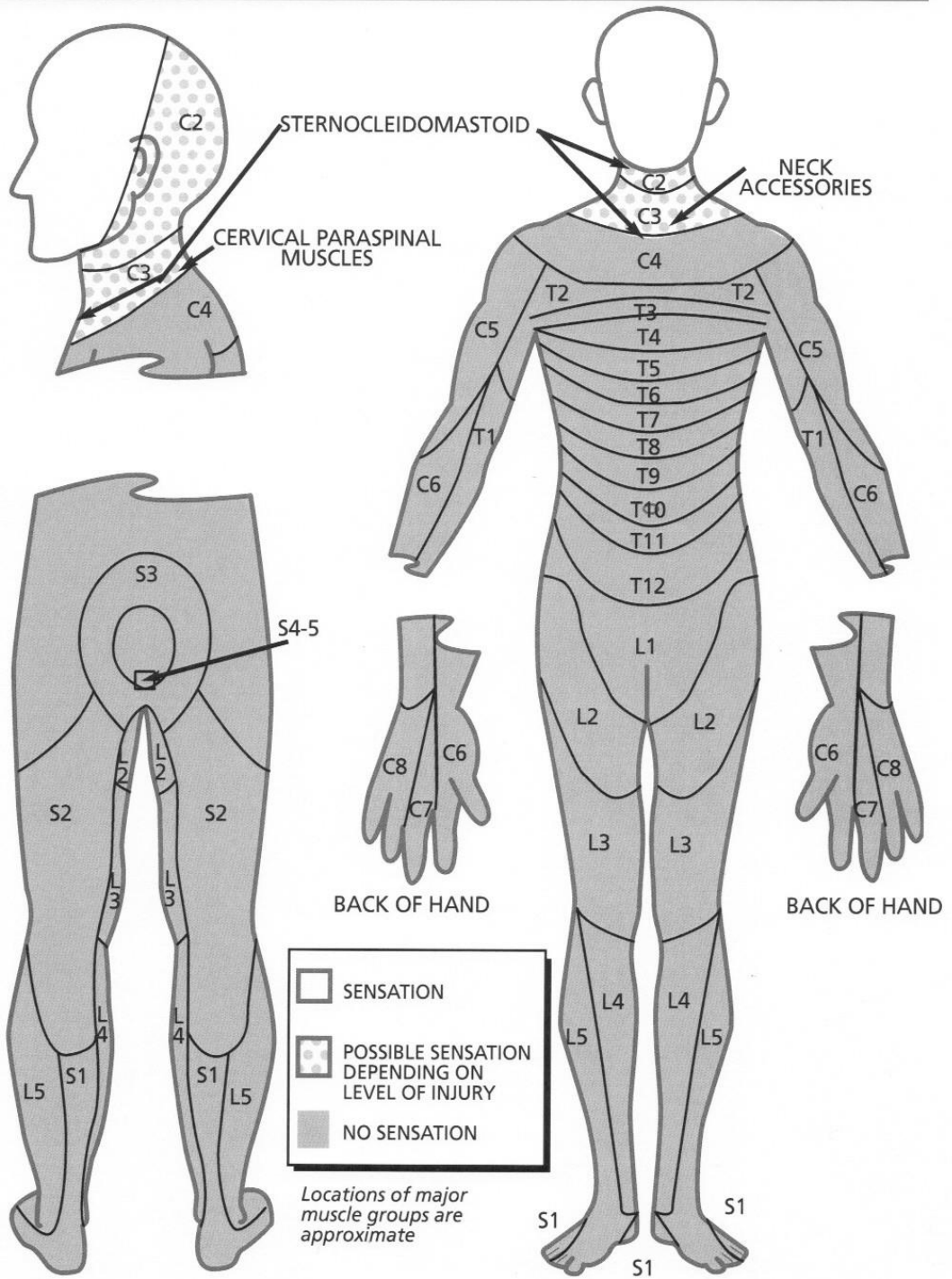
It also has 33 bones, called vertebrae. Each vertebrae is associated with a spinal nerve. A simple system of one letter and one number acts as shorthand for the SCI (figure 1). The letter shows the section, and the number shows the injured nerves. The level of injury determines what parts of the body lose muscle and sensory function. The severity or completeness of the injury determines whether some or all motor and sensory function is lost. This guide is intended for someone with complete paralysis below C1-3.

Cervical (neck) injuries usually result in four limb paralysis called tetraplegia. A person with complete C1-3 SCI is able to speak, swallow and control head movement, but they do not have the ability to move their arms or legs. They will lose the ability to cough and breathe. Injuries at the C1-3 level require mechanical ventilation.

The position of key muscle groups still working after a C1-3 spinal cord injury are indicated in figure 1. They may include:-

- Sternocleidomastoid (rotates and flexes neck).
- Cervical paraspinal muscles (extend neck).
- Neck accessories (assist with speech and swallowing).

FIGURE 1—LEVEL C1-3 SENSATION DIAGRAM



Other factors affect outcomes. They include:-

- Health before injury.
- Current general health status and body build.
- Age.
- Associated injuries.
- Secondary complications.
- Support network of family and friends.
- Financial situation.
- Home and work environment (accessibility; attitudes).
- Access to and availability of healthcare and rehabilitation services.
- Participation in community activities.

What Activity Outcomes can I Expect after a C1-3 Spinal Cord Injury?

Table 1 lists life activities, such as breathing, eating, dressing and moving around. For each activity, it explains what many people with a C1-3 SCI can reasonably expect one year after injury and can help in setting short and long term goals.

It is important to understand what “reasonably expect” means. **Table 1 uses averages.** In the real world, outcomes vary from person to person for the same level of injury. Your treating team will help to set goals with you since outcomes are very specific to each person.

Important:

Table 1 is a general guide for expected outcomes for a C1-3 complete SCI. **It’s a goal to work toward, not a guarantee!** For every activity listed, some will not be appropriate or achievable for everyone with a C1-3 SCI. Your outcomes may not match table 1 within the timeframe suggested or you may exceed the goals listed. The expected outcomes listed here are based on research and clinical experience, but they’re based on other people with SCI – not on you.

The outcomes in table 1 are described in terms of the need for help with specific activities. The table has three categories:-

- Independent (I).
- Some assist (S).
- Total assist (T).

Activities including mobility and communication have more than one category marked. It may be possible to have some movement of your neck with a C1-3 spinal cord injury. However outcomes vary from person to person.

Most C1-3 injured people need a ventilator to assist in breathing. Individuals will require the total assistance of a carer for most activities. The level of assistance required will be dependent on what equipment is available to the individual and the accessibility of their environment. For example; a person with a chin driven power wheelchair or high-tech computer access may be independent in their mobility and communication, but will require assistance for set up.

Special equipment you may need or want for certain activities is also listed. Your rehabilitation treating team may have different suggestions. Equipment needs, like outcomes, may change over time.

24 hour personal assistance will be needed.

TABLE 1

Assistance Type: I = Independent, S = Some Assist, T = Total Assist

Expected Outcomes – Level C1-3 Complete Spinal Cord Injury

Activity	Assistance Type	Equipment
Breathing	T	<ul style="list-style-type: none"> • May require assistance to clear secretions. • Bedside ventilator. • Portable ventilator. • Suction machine. • Back up for power failure. • Vent tray for wheelchair.
Eating	T	
Bathroom functions: • Bowel care • Bladder care	T T	If roll in shower available; <ul style="list-style-type: none"> • Padded reclining / Shower commode chair.
Personal Care: • Dressing	T	Bathing equipment <ul style="list-style-type: none"> • Shampoo tray. • If roll in shower available; • Handheld shower. Padded reclining shower commode chair.
•Grooming •Bathing	T T	
Positioning/Pressure Relief	I/S T	Wheelchair:- <ul style="list-style-type: none"> • Power recline, and or tilt function. • Pressure relief cushion. • Postural support and head control devices as needed. Bed:- <ul style="list-style-type: none"> • Speciality bed or pressure relief mattress.
Mobility: • Bed	T	Bed:- <ul style="list-style-type: none"> • Full electric hospital bed with Trendelenburg feature and side rails.
• Transfers	T	Transfers:- <ul style="list-style-type: none"> • Power or mechanical hoist with sling.
• Wheelchair use	I T	Wheelchair use:- <ul style="list-style-type: none"> • Power recline and/or tilt wheelchair with head, chin or breath control or standard upright. • Manual recline wheelchair.
• Standing	T T T	Standing:- <ul style="list-style-type: none"> • Standing frame. • Tilt table. • Hydraulic standing table.
•Transportation		Transportation:- <ul style="list-style-type: none"> • Attendant operated van eg. lift tie down.
Communication	I/S/T	<ul style="list-style-type: none"> • Mouthstick. • High tech computer access. • Environmental control unit. • Adapted equipment.
Homemaking	T	

With a C1-3 injury, you should be able to explain everything an assistant needs to know about your care but you will require assistance to perform all activities of daily living, personal care to meet basic care and safety requirements.

Modifications to your home and workplace are likely to be needed to allow you to do as much as possible. **Safety and accessibility are significant considerations.**

An Occupational Therapist will need to visit your home to consider any changes that will be needed. A visit to your workplace may also be necessary. This should provide you with helpful architectural and other changes that may help you accomplish as much as possible.

Activities can change over time. Regular review will be needed both during your in-patient admission and after discharge. They can improve, lessen or both. The treating in-patient or spinal out-patient team may be able to help meet your needs with different services, assistance, equipment or repairs.

It is important to know that changes and improvements in function will not happen all at once. **Rehabilitation is a lifetime process** ... it does not end when you leave the hospital. In order to regain control of your life after a spinal cord injury, you will need a sense of purpose, discipline and support.

A spinal cord injury does not necessarily lessen satisfaction with life. Life satisfaction is your answer to the question, "Is my life going well, according to the standards that I choose to use?" Your degree of life satisfaction is **not** strongly related to your type or your level of SCI. For example, some people with C1-3 spinal cord injury can be more satisfied with their lives than people without a spinal cord injury or with other types of SCI. You will notice that your perspective on life will change with time. As one individual noted, "The person I am after a spinal cord injury is different, but improved from the way I used to be. However I still wouldn't mind visiting the old me". Satisfied people have been found to take better care of themselves, maintain their health, and prevent medical complications.

Your personal satisfaction is more related to ways you connect with others in the community. Therefore, your ability to form friendships or be a partner, student, employee or volunteer is very important. For people with high cervical injuries, it requires effort to manage personal care, get out in the community, and make productive uses of time. Sometimes a brief review of participation outcomes (social life in the community) can help you stretch your imagination and think of ways to improve things (see table 2 below).

TABLE 2**Question and Actions**

Questions	Actions
Is there adequate money to meet housing, food and healthcare needs?	<ul style="list-style-type: none"> • Review benefits with your NSIC Case Manager
How do I make and keep friendships and relationships?	<ul style="list-style-type: none"> • You can discuss strategies with your psychologist. Talk to your peers – many long term friendships are established through rehabilitation.
How can I best organise and manage my care?	<ul style="list-style-type: none"> • Discuss this with your Case Manager. You will have access to an Independent Living programme and your treating team will help you plan the way you receive your care.
How can I feel useful and productive?	<ul style="list-style-type: none"> • Discuss employment, volunteer, and education options with your Occupational Therapist and the Employment Clinic.
How do I get around in my community?	<ul style="list-style-type: none"> • You can discuss transportation and community mobility with your Occupational Therapist and your therapist will assist you in trying some local options out.

Meaningful activities are available to people with even the more physically limiting spinal cord injuries. During rehabilitation, you will learn to become an expert on spinal cord injury so you can educate your family, friends and partners. In addition to education, it is important to learn to express your needs. This is sometimes difficult to do, but is important if you are to succeed in developing a satisfying life in which you make meaningful contributions to your community and achieve important things you want.