Flashcards Spinal Cord Injury



These flashcards contain information about working with people with spinal cord injury in low resource areas.
These Flashcards are made for the use of fieldworkers.
These flashcards are based on the information about spinal cord injury (SCI) from the RehApp

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The goals of the flashcards are:

- To meet the needs of people with disabilities and their families.
- To improve knowledge and skills of fieldworkers in providing basic (functional) rehabilitation services for people with disabilities and their families.
- To enhance participation in daily, family and community life.
- To improve the quality of life of people with disabilities and their families.
- To support you (as fieldworker) in the process of guiding a family/person by providing you with a resource you can keep with you on your phone (offline) or in your bag.

What can you do with these flashcards:

- To help guide your visits to persons with SCI and their families
- Make an inventory of the needs of the person with SCI and his/her family.
- Learn about the implications of a disability for the person and their family.
- Use them to do an assessment.
- Use them to set goals for a person with SCI.
- Use them to help you discuss interventions with the family.
- Use them to help you keep client records.
- Use them to help you monitor process.

Index:

Note: These flashcards consist information about Spinal Cord Injury. These cards don't replace the knowledge and skills of doctors and therapists. We advice you to seek their advice first.

Information about Spinal Cord Injury	
	Introduction
	Body functions & structures
	Activities & Participation
	Personal factors
	Environmental factors

Index

Spinal Cord Injury

Index

Spinal Cord Injury: content

Introduction:

- ❑Introduction Spinal Cord Injury (SCI)
- ❑Living with SCI
- ❑Inclusion in society
- ❑Symptoms of SCI

Body functions & structures:

- ❑Staying healthy and preventing complications
- ❑Exercises
- ❑Arm function after high level SCI
- ❑Complications

Activities and Participation

- ❑Domestic tasks
- ❑Eating and Drinking
- ❑Dressing
- ❑Moving around
- ❑Transfers
- ❑Wheelchair mobility
- ❑Occupation
- ❑Vocational training, education, work

Participation:

- ❑Community inclusion
- ❑Occupation
- ❑Sexuality
- ❑Transport
- ❑Vocational training
- ❑Personal feelings
- ❑Acceptance phases
- ❑Changed roles
- ❑Sexuality
- ❑Peer counselling

Environmental factors:

- ❑Independent living in the community
- ❑Transport
- ❑Moving outdoors
- ❑Home modifications
- ❑Bathroom modifications
- ❑Wheelchair seating

Card 1

Introduction

Introduction Spinal Cord Injury (SCI)

A spinal cord injury (SCI) involves damage to nerves in the spinal cord, resulting from trauma or disease. The spinal cord connects the brain to the rest of the body, so this injury can affect functions and sensations in parts of the body beneath the level of the injury. Symptoms of spinal cord injury depend on the severity of injury and its location on the spinal cord. The main features are paralysis of the muscles below the level of the injury (loss of motor control), combined with loss of feeling.
The majority of SCI are due to preventable causes such as road traffic accidents, falls, disasters or violence.

Living with SCI

Most people with SCI can learn to be independent in all activities while others, especially those with injury high in the spinal cord, need a personal assistant to enjoy a normal lifestyle. Most will need a wheelchair. The house and environment need to be accessible in order to be able to participate in work and community life. Staying active and doing regularly exercises are important to lead a healthy, active and fulfilling life.

Inclusion in society

Access to assistive devices and an accessible environment makes active participation in economic, social and/or educational activities possible.



Misconceptions, negative attitudes, no access to assistive devices and inaccessibility of the environment may result in the exclusion of people from full participation in society. Children with spinal cord injury are less likely than their peers to start school, and once enrolled, less likely to advance. Adults with spinal cord injury face similar barriers to economic participation, with a global unemployment rate of more than 60%.



Card 2

Introduction

Symptoms of SCI

Injury at Neck level – quadriplegia



- Bladder and bowel problems
- Paralysis, and no feeling in legs and all or parts of arms
- Need support to sit
- Breathing problems
- Need a wheelchair to move around (which may need to be pushed by another)

Injury at chest level



- Use of arms, but not fully
- Paralysis and no feelings in legs
- Bladder and bowel problems
- The person can push self in wheelchair

Injury lower down in the back (paraplegia)

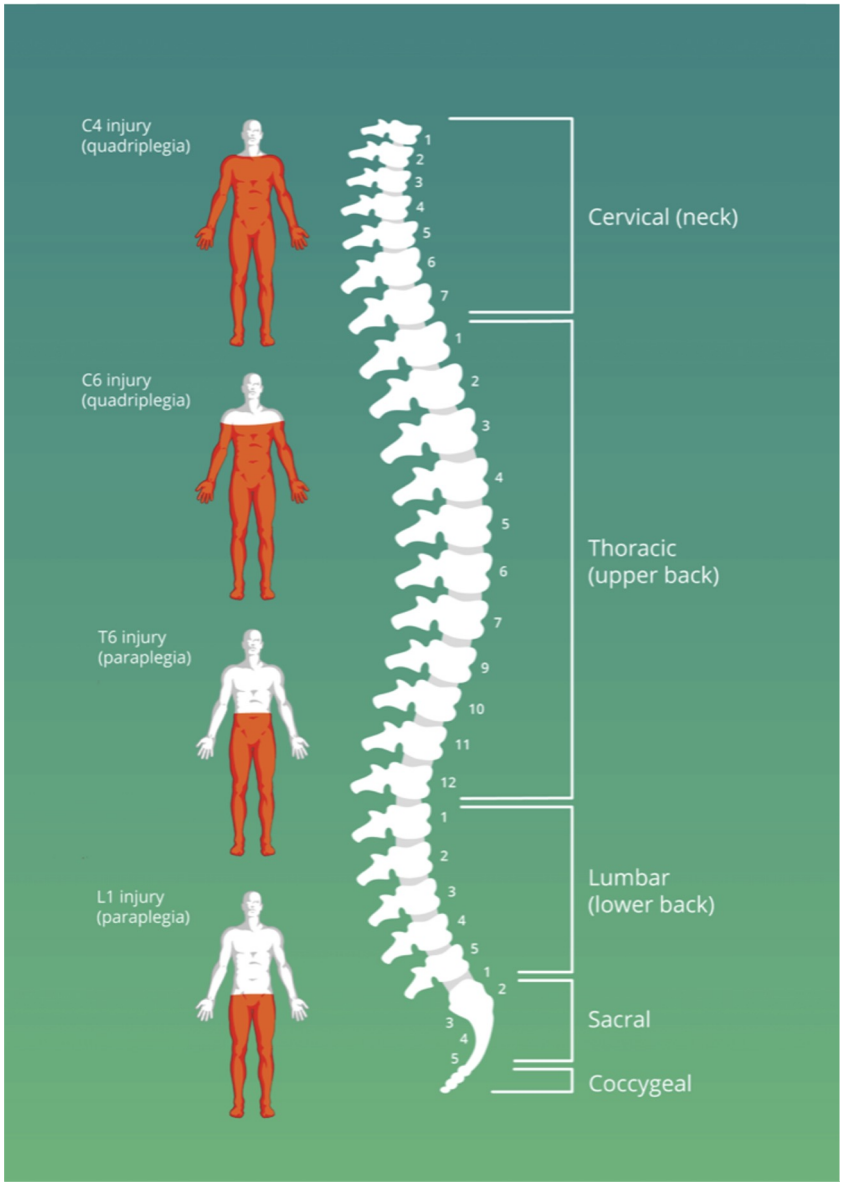


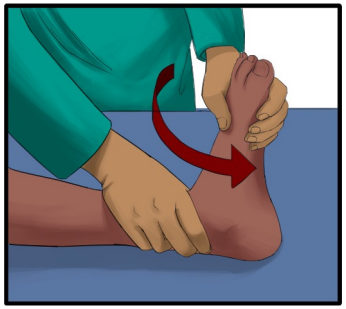
- Full use of arms
- Some use of legs
- Some control of bladder and bowel
- May be able to walk (short distances) with crutches or walking frame

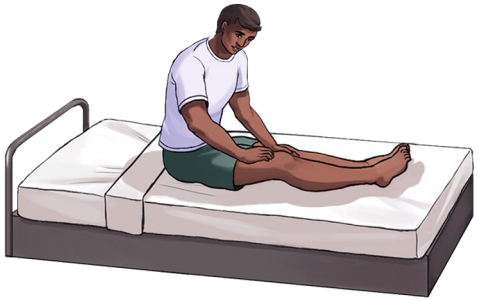
Many people with spinal cord injury experience chronic pain.

Mortality rate for people with Injury at neck level is high, especially in low resource settings.

Red: part of the body where muscles are paralyzed and sensation is lost.







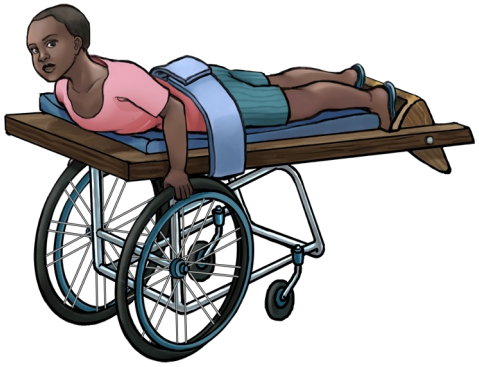




Body functions and structures:

Information and

Actions to take





Card 3

Body functions and structures

Staying healthy and prevent complications.

The life of a person with SCI changes suddenly and dramatically. The person needs to learn a lot of new skills to manage daily life. Usually after the injury the person is admitted to the hospital and later maybe to a special rehabilitation centre where they may have learned how to be independent in daily life.

Persons with SCI have the risk to develop complications like wounds/pressure sores or bladder infections. That can have a negative impact on the quality of life and can even be life-threatening. Staying healthy and prevent complications is very important.

Actions to take:

Daily for persons who lost feeling in buttocks and legs

- Shift body position every 15-30 minutes
- Keep the skin clean and dry and check it everyday 2 times for sores or injuries.
- Eat healthy foods and drink enough fluids
- Exercise and be as active as able

For all: Plan activities and exercises into the daily routine

Discuss with the person with SCI:

- What is s/he doing now independently? If not independent: think of ways to increase it a little.
- How to do more: when can the person add (small) chunks of activity into the daily routine, like helping with a household activity, playing a game?
- How to keep motivated: setting small goals and tracking progress are good ways to maintain motivation
- Discuss if there are any health concerns which needs to be addressed prior to starting with adding more activities to the daily program
- Discuss with others (experts or other people with SCI) to get more suggestions on appropriate interventions as each situation is different
- Connect the person with others with SCI, in order to facilitate doing sports or leisure activities and get and stay motivated.

Exercises

Why exercise?

- Improves independence
- Strengthens breathing muscles
- Reduces constipation
- Improves self-esteem and self-confidence
- Improves circulation
- Prevents complications such as urinary tract infections, pressure sores and respiratory infections
- Reduces risk for diabetes and heart disease

Precautions when doing exercises

Skin problems

Be careful that transfers and equipment do not cause frictions or pressure on the skin. Monitor the skin!

Overuse injuries

Choose exercises that do not involve the muscles already used a lot during daily activities, such as the muscles to push a manual wheelchair. Focus then more on for example the rump.

Do not train to intensive

Talk-test: talking while doing exercises should be possible. Only short spurts of (very intensive) exercises (which make it difficult to talk) and are allowed.

To prevent blood pressure drops: Exercise slowly and progress gradually.

Spasticity

Spasticity may make it difficult to do an activity well or it may throw the person out of position while doing an exercise. If the person has a lot of spasticity, have someone with him/her for the first time of trying a new exercise. Ensure safe positioning, for example use pillows beside a person when practicing sitting more independently.

If the spasticity the person normally experiences changes look for complications which could be the cause and/or consult a medical doctor.

Pain

Exercises should not be painful!

Not feeling well during the exercises

When the person starts to feel dizzy or (little) nauseated stop immediately, lift the person's head and lower the legs.

If the person gets severe headache, sweating, blurred vision or shortness of breath: check the card about complications.

Card 4

Body functions and structures

Card 5

Body functions and structures

Exercises
There are 3 kinds of exercises, which are all important.

1. Stretching exercises
2. Strengthening exercises
3. To improve condition (Aerobics)

1. Stretching exercises:
People with SCI should stretch regularly to prevent and treat stiff muscles and joints. They should focus on shoulders, hips, knees, and ankles, because these are common areas of tightness after SCI. Stretching can be done by themselves or with help from a trainer, therapist, aide, family member, or friend. They should stretch most days of the week. Start out by gently stretching each muscle group for at east 30 seconds. Repeat the stretch a second time, trying to go a little bit further.
See next card for more information.

Stretching before and after aerobic exercise and strength training is best.

2. Strengthening exercises
Muscles used for pushing the wheelchair get a lot of practice already. It is important to strengthen the other muscles as well, like the muscles at the back of the arm and the muscles of the back. This will help to maintain stability and avoid overuse injuries.
Guidelines:

- ➔ Start with low weights
- ➔ 3-5 sets of 10-15 repetitions;
- ➔ Moderate intensity; 2-3 sessions per week;
- ➔ Maintain good quality of movement; otherwise reduce weight or reduce the number of repetitions.
- ➔ Avoid painful positions—it should not hurt!
- ➔ Don't do the exercises every day; have at least one day rest in between. Prevent overuse injuries.

Gardening and household tasks can strengthen the muscles as well!

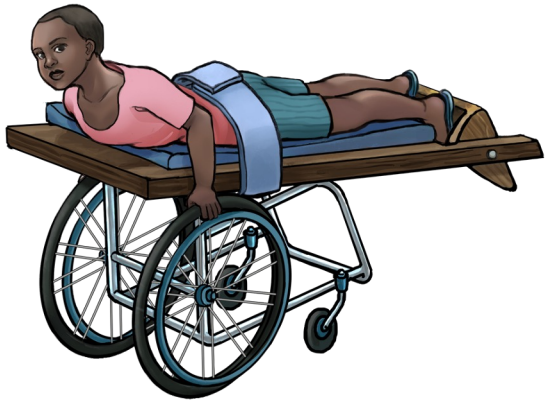
3. Aerobics
Activities that increase the heart rate and breathing improve the condition. This can be wheelchair 'racing', sports.
Minimum: 3 times a week for 30 minutes, preferably 60 minutes.
Note: ***think about the talk-test*** to measure that the intensity of the exercises is not too high!

Stretching exercises for the muscles which are paralysed

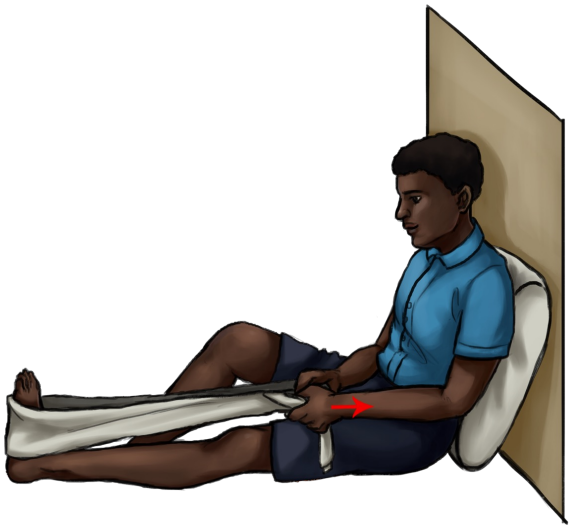
Weak and paralysed muscles can become short, which will cause stiff joints. Stiff joints will make it more difficult to do activities of daily living like transfers, dressing or bathing.

Whenever possible the person should learn to do the stretching him or herself.

- ➔ Do stretching gently, and do NOT apply aggressive stretch!
- ➔ Do it every day
- ➔ Make the person spend at least some time each day in positions that “open up” the bended joints. Daily, for around 30 minutes, lie on the stomach, preferably with the feet off the bed.
- ➔ If possible, add with some push-ups with your upper body while your hips and legs remain on the bed. This can be done on a bed, but also on a gurney/prone cart (which are used to heal sores)
- ➔ Appropriate positioning is more effective and less costly than passive movements.



- ➔ Stretching exercises for the knee and ankle muscles.
  - ➔ Do this for each leg.
  - ➔ Hold for 20-30 seconds, no bouncing.

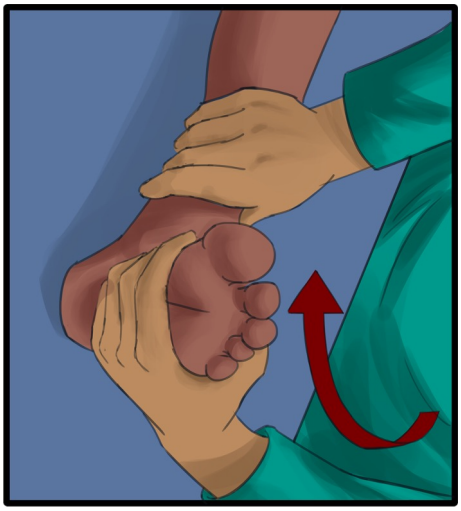


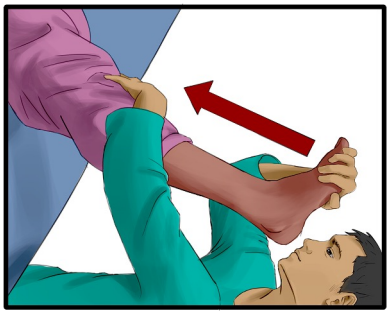
Card 6

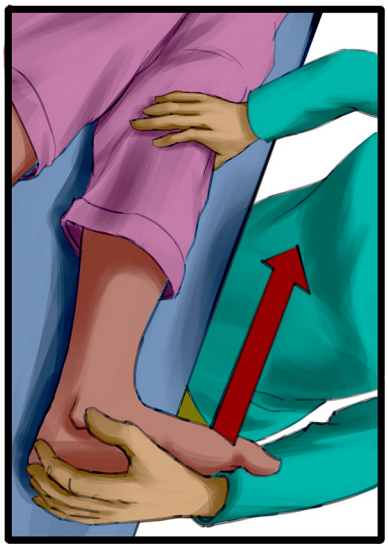
Body functions and structures

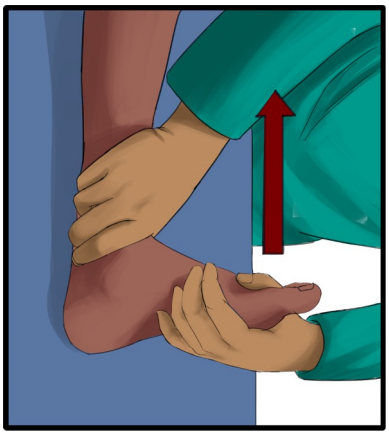
Body functions and structures

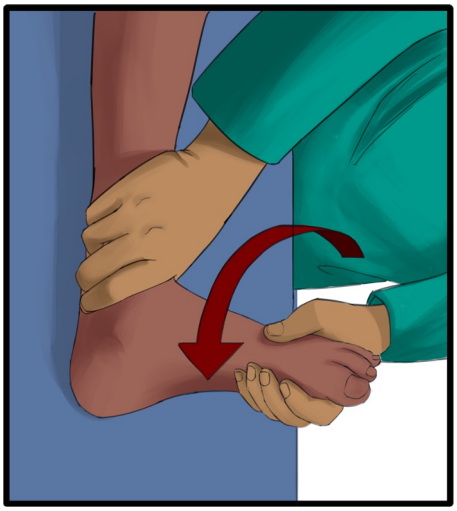
Card 7











Stretching if the person can not do it him/herself: leg and ankle.

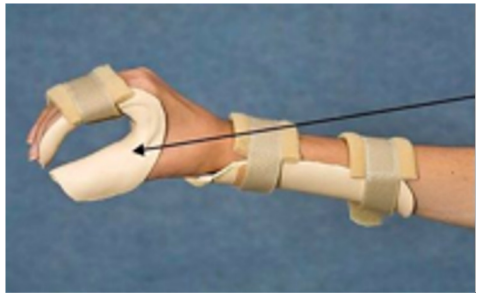
Arm function after high level SCI

People with injuries at the neck (C=Cervical/neck) have limited use of their arms and hands. How much use depends on the injury.
Some have to use chin or head controlled technologies and power wheelchairs if available. If not available they require support of an assistant to push a manual wheelchair.
Others will be able to carry out simple hand activities such as eating, and others will be able to use hand and wrists, with or without support by splints or other assistive devices.
Persons with high level will need a personal assistant for most daily activities.

Actions to take

- Prevent and treat contractures of the legs and arms, using stretching and passive movements every day.
- Ensure good position when sitting in the chair or when sleeping
    - Don't let the hand drop down while sitting or sleeping, which would cause swelling, and treat when needed, e.g. by splinting.
    - Ensure that the arm under the elbow is supported when sitting
- Let the person help and do as much as possible to keep or improve strength in arm and hands.
- Where necessary, provide splints/assistive devices such as on the photo. Refer to a occupational therapist or similar specialist for splints and other aids.

Examples of commonly used splints for persons with SCI



1. Resting splint, used to keep the hand in good position. To be worn at night.



2. To hold position for writing on paper or for use of mobile phone or tablet with stylus..



3. Typing splint.

Card 8

Body functions and structures

Card 9

Body functions and structures

Complications

When to consult a doctor or specialist as soon as possible:

If the person experiences severe headache, sweating, blurred vision and shortness of breath. Provide first aid immediately as this is potentially life threatening if not properly managed.

•Lift the person's head and lower the legs, e.g. by using a pillow.

•Remove any compressing clothes, such as stockings, neckties and belts.

•Check the bladder and bowel and empty these if necessary.

•Check the skin for damage caused by such things as ingrown nails, insect bites, etc.

Go immediately to the doctor if this does not stop the symptoms.

When the person with SCI gets:

Dizzy, a mild fever, change in skin colour of a leg and local swelling and warmth with change in skin colour. Go immediately to the doctor.

Breathing problems

There can be sudden problems in breathing. When you become aware of sudden problems in breathing while the person is sitting up, put him/her in half lying position and remove any restrictive clothing (such as stockings, neckties and belts). If it does not get better consult a doctor.

Urinary tract infections

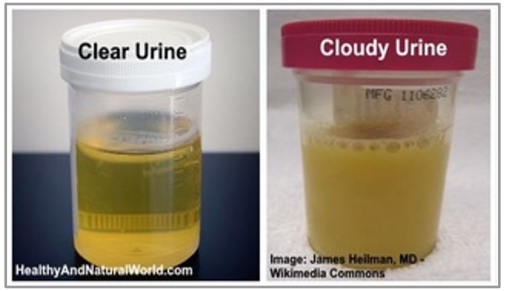
People with SCI have increased risk for infection of the urinary tract (urethra, bladder and kidneys). These infections should be prevented as much as possible and treated promptly when they arise.

How to prevent urinary tract infections

- Maintain proper hygiene: keep body, underwear and catheter clean.
- Ensure complete emptying of the bladder every 4-6 hours.
- Drink sufficient fluids: on average around 100-125 ml per hour, approximately one glass every 2 hours.
- Avoid accidental pulling on a catheter by properly strapping the bag.

Consult a specialist as soon as the signals described below are observed!

- Incontinence
- When the urine looks 'cloudy'
- Nausea
- Fever
- Malaise



Card 10

Body functions and structures

Toileting

After a SCI, the person usually loses control and sensation in the bladder and bowel. In the early stages after the injury, accidents involving bladder and bowel often occur, which greatly affects the person's confidence. If bladder and bowel management is not carried out early on, serious complications can occur, such as repeated bladder infections, constipation, bladder stones, kidney failure or damage that may even lead to death.
Not being able to control the bladder or bowel also can cause the person feeling afraid to go outside. It also may add stigma by people around.
Being continence is also the best prevention against pressure sores.

Bladder management

The most common urinary problems for persons with SCI are: the inability to fully empty the bladder; the inability to feel if the bladder needs to be emptied; and the inability to control muscles for voiding. One can use diapers or self made pads to use in the underwear or choose between different catherisation techniques.

NOTE: make sure the person or personal assistant gets proper training in catherisation technique.

Bowel management

People with SCI may be unable to feel if the bowel is full and control muscles that prevent defecation. There are several options for managing bowel continence.

1. A good, stable diet with lots of fiber (e.g. vegetables, fruit, potatoes, bread and nuts).
2. Sufficient intake of (non-alcoholic) fluids.
3. Regular bowel emptying program: try to pass stool every day (or every other day) at the same time. Do it, even if the person had an accidental bowel movement at another time. Eventually, the body will adjust to the schedule and the stool will come out more easily at a regular time.

NOTE: only after being trained bowel wash technique, stimulation of bowel reflexes or medication can be applied.

Privacy

It is important to respect privacy as much as possible. Select and test the most appropriate strategies, depending on the person's preferences, abilities and preservation of health status.
Some people prefer to use a mobile shower commode in order to avoid difficult transfers to the toilet. Others prefer using the toilet.

Card 11

Body functions and structures

Pain

People with SCI can experience pain (e.g. in joints and muscles) above the lesion just like everyone else. However, also in locations with little or no feelings body parts may be painful. It is often described as shooting pains with burning or tingling sensations. We call this neuropathic pain. It can be a very frustrating symptom. It can go away on its own but is often chronic.

Actions to take

- Sometimes activity and movement can reduce the pain.
- Aim to reduce pressure sores and stress.
- Explore ways to alter the pain experience using body awareness and concentration techniques.
- Always consult a medical expert for advice and options for handling pain!
- Education about positioning and pressure relief.

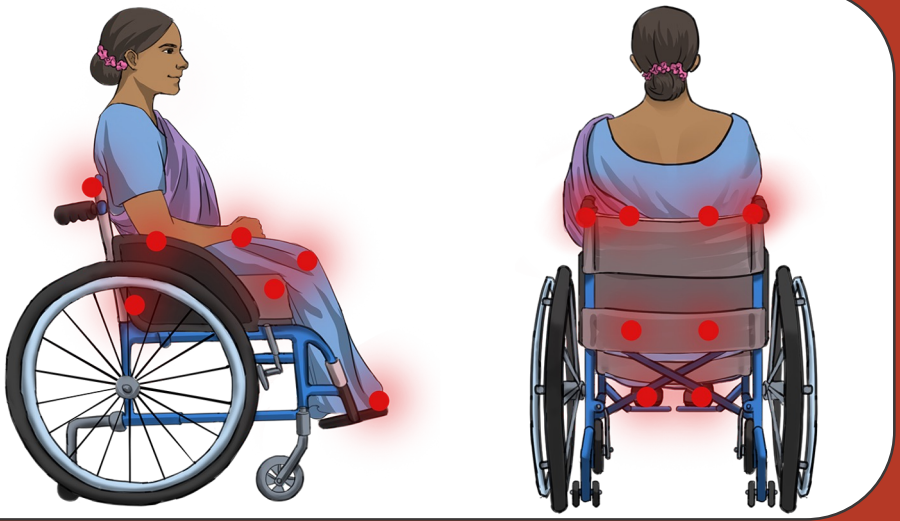
Prevention of back and shoulder pain

People with SCI are sitting in their wheelchair for long times per day and rely on their arms for many activities. They run the risk of developing (chronic) back, or shoulder pain, or pressure wounds.

Actions to take

- Review their wheelchair seating. The elbows should not be bending more than 90 degrees while propelling the wheelchair.
- Review the place where the person spends most of his/her time (e.g. is the table too high/low?).
- Strengthen their shoulder, chest and trunk muscles through exercises.
- Prevent overburdening of the body via building in physical breaks and lower the number of e.g. transfers.
- Refer to a clinic or health centre if the pain does not go away.
- Refer to a therapist or technician if the wheelchair needs adaptation.

Red points are the places with risk of developing chronic pain or pressure wounds.



Actions to protect the skin: Prevention is better than cure!

- Monitor risky spots: places where bones are right under the skin, where clothes may press against, or where the skin gets wet, for example the buttocks or the heels. Use a mirror for difficult to check areas.
- Look for changes in the skin. Skin turns darker or redder under constant pressure. **If the skin colour does not get back to normal within 20 minutes, address the cause immediately!** The person needs to lie on the belly, until the redness disappears or darkened parts disappear (for those with black skin colour)
- Avoid wearing too tight clothing
- Encourage physical activity and movement
- Elevate the head of the person's bed as little as possible.
- Maintain a healthy, nutritious diet.
- Keep the skin dry and clean (remove urine and faeces) by good bowel and bladder management.
- In bed: switch from one side to the other at least every 3 hours. Help the person if needed.
- In the (wheelchair): encourage the person to lean forward for at least 15 seconds every 15 minutes, then lean backwards or lift their buttocks off the chair (with assistance if necessary). Use appropriate cushions to prevent the buttocks from having contact with hard material.





If a sore has already formed:

- Get help from a doctor or nurse.
- Don't put pressure on the sore area!
- Keep the area clean. Wash it gently 2-3 times per day with clean (boiled and cooled down) water.
- Eat healthy food for quicker healing: food rich in protein such as beans, eggs, fish and milk.





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Actions if the sore has dead tissue:

- Dead skin tissue needs to be removed to help the wound heal. Ask a specialist nurse for help and instructions.
- If you are qualified to treat wounds, try to clean the wound with a saltwater (saline) rinse carefully. This helps to remove the dead flesh until you reach healthy red flesh or bone.
- Once the sore is free of dead flesh, fill it 2 times a day with organic, pure, clean, **fresh honey** readily available in rural areas, to prevent or reduce infection and help healing. This can be pressed deep into the sore.
- Cover with special clean and non-sticking dressing to keep the skin moist and to heal.
- **If the sore does not heal within 10-14 days or if it returns: visit a clinic!**



Card 12

Body functions and structures











Activities and Participation:

Information and Actions to take

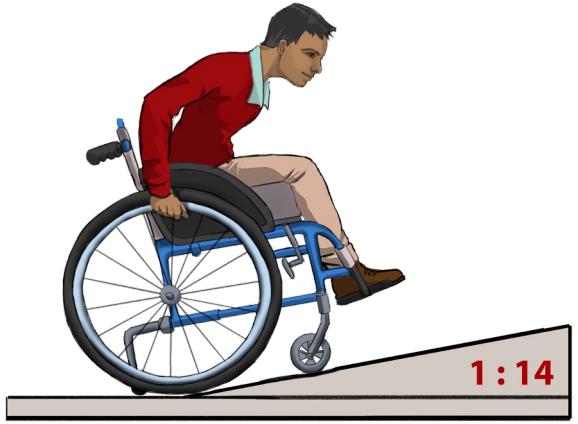












Domestic tasks

The ability to perform domestic tasks -such as cooking, washing, cleaning and home and garden maintenance- largely depends on the accessibility of the homestead. Often, the environment or tasks can be adapted to the abilities of the person with SCI. For instance, in countries where household tasks are usually performed on or close to the ground, a simple low-cost device on wheels can be constructed locally. Try and search for local solutions as far as possible.

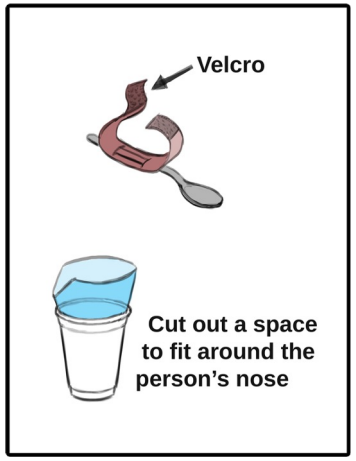


Eating and Drinking

For people with an injury below C8, eating and drinking independently is no problem at all.

For people with high level injury (cervical/neck), eating and drinking:

- May be only possible when supported.
- Drinking may be possible with a large straw close to the mouth.
- Eating and drinking independently may be possible by using a hand splint or adapted cutlery. Cutlery can be attached to the hand for example with velcro. Or use fabric or rubber strap around the handles to enable grasping. It depends on the functioning of the arm and hand.
- When the shoulder function is limited, it may help to keep the elbows on the table and move only the forearms.



Card 13

Activities and participation

Card 14

Activities and participation

Dressing

People with high level injury may be partially able to dress themselves while people with injuries below the neck can usually dress independently. Sitting on the bed is often the best position for getting dressed, provided the joints and muscles are flexible enough to maintain balance and reach the toes. Dressing will be easier with an appropriate selection of clothes (lose-fitting, light-weight, large zips/velcro), or with modified clothes (e.g. a zip all down the side of the trousers, difficult fasteners replaced by easier ones, elastic used instead of shoelaces).





Card 15

Activities and participation

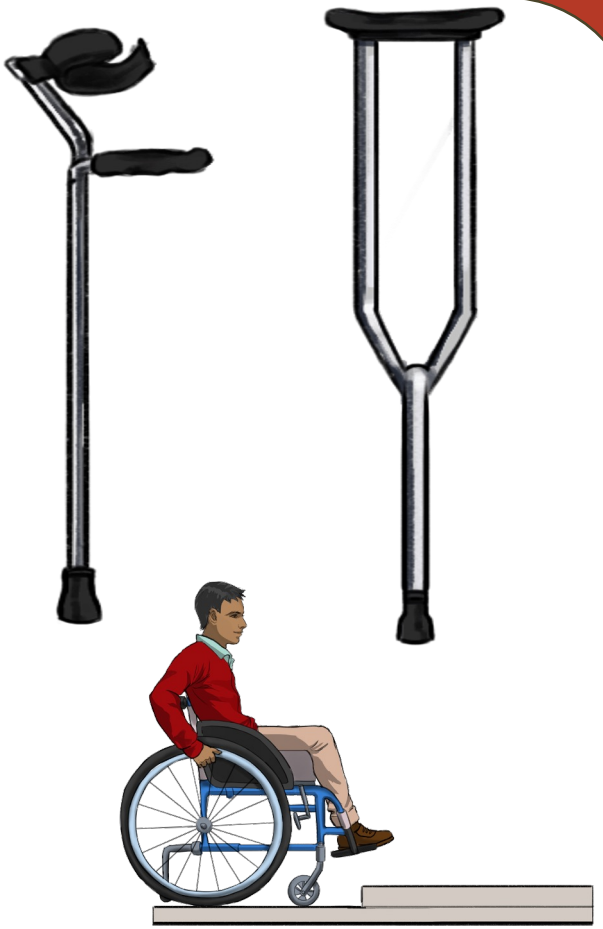
Moving around

Some people with low injuries have the ability to use the legs and may be able to use mobility aids to move around.

The use of mobility aids to walk and move around is based the ability to use the legs, combined with personal motivation (e.g. it may be easier to move around in a wheelchair than to walk with splints/braces or crutches) and external factors (e.g. financial means, availability of wheelchairs). The distance to be covered also has to be considered.

- Short distances (inside and/or outside the home) may be covered using technical aids such as splints/braces and crutches. Often, these can be easily made from local resources.
- Long distances can be covered using wheelchairs that are manually or electrically powered. You can get information at the local health centre or rehabilitation facility on what kind of mobility aids are available and at what cost. Be aware that electrical wheelchairs are very expensive, may not be appropriate for rough surfaces and remote places do not always have electricity available.

Many persons with SCI will need a wheelchair





Card 16

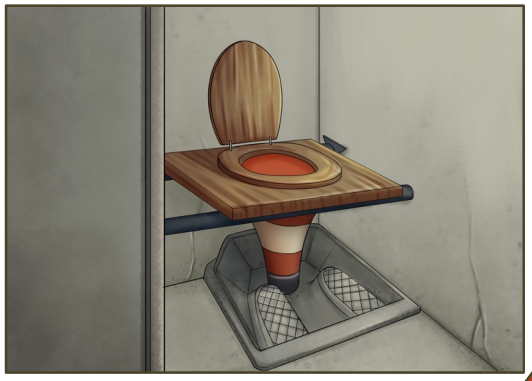
Activities and participation

Pay attention to the following procedures in close partnership with the person with SCI:

- Monitoring of water and food intake! Enough water and nutritious food is essential for preventing problems like bladder infections!
- Modification of bathrooms to support toilet use such as use of toilet chairs, ramps towards toilets, toilets that are wide enough and respect privacy.
- Stimulating daily bladder and bowel management techniques and consult a specialist for this







Card 17

Activities and Participation

Transfers

Some people with SCI will be able to learn and do transfers themselves, others might need help. Transfers need to be practiced to increase mobility. There are many different types of transfer, each requiring slightly different techniques.

Avoid the use of overhead lifting points, such as handles above the bed or roof handles in a vehicle, as these are likely to cause shoulder problems.



Also, try to minimise the number of transfers carried out each day to prevent shoulder injuries but do change positions throughout the day to prevent pressure sores.

Horizontal transfer between wheelchair and bed

A wooden transfer board can be used to bridge the gap between the two seats like the picture. It is better though to lift the buttocks than slide over the surface, to prevent sores.



1. Remove the detachable armrest if possible.
2. Move the buttocks to the front edge of the seat.



3. Position the feet on the footrest (some people prefer to first place their feet on the bed or in the car, depending on the target seat).



4. Position the hand (closest to the bed) close to the body, and the other hand forward and away.
5. Lift and shift the body onto the target seat with the head rotating towards the pushing hand.





Card 18

Activities and Participation

Horizontal transfer between chairs or chair and toilet





Vertical transfer

When moving from the floor to the wheelchair, you can use a vertical transfer requiring 6 steps. For the assistent: let the person do as much as possible by him/herself to prevent problems such as back injuries due to heavy lifting.



1. Place the wheelchair next to you at a 90-degree angle. Put the wheelchair on the brakes.



2. Position the legs with the feet as close to each other possible.



3. Position the hands with the dominant hand forward and away from trunk onto the edge of the wheelchair and the other hand close to the hip.
4. Lift and rotate the hips to the wheelchair.



5. Position the buttocks on the wheelchair.



6. Move into an upright position.

Card 19

Activities and participation

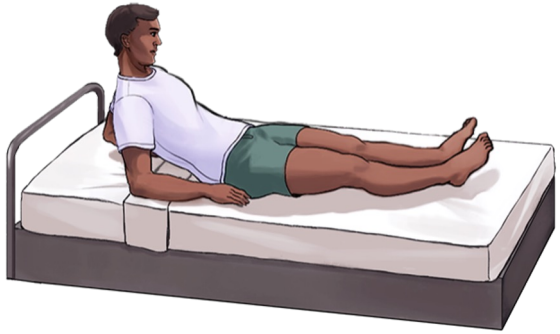
Transfer: Rolling to sitting

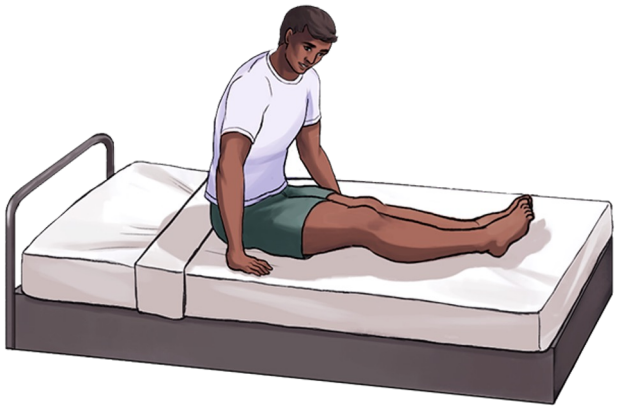
Rolling is important for changing position in bed, pressure relief and moving from lying to sitting. People with C6 level injury and lower can roll from their back to their side. Where the torso and legs cannot be used, the head, neck and upper limbs can be used to generate momentum by repeatedly swinging the arms across the body. For C6 levels, the shoulders initiate the movement.

Lying to sitting position

For people with paraplegia (torso and legs affected), moving into long sitting (sitting with straight legs) is comprised of 2 key stages.

1. While lying on the side, pushing up through one or both arms to lift the torso off the bed.
2. Extending the elbows and bringing the torso over the hips to move into sitting. People with C6 tetraplegia (partial or total loss of use of all four limbs and torso) will bear weight through the elbows, move on the elbows towards the legs and pull into long sitting.







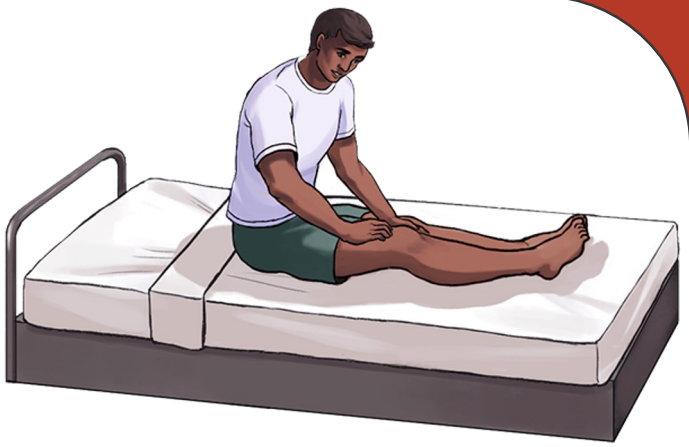
Card 20

Activities and participation

Sitting

People with SCI and lower limb paralysis need to learn how to sit without support. This may be challenging due to paralysis, loss of sensation, and loss of sense of balance. People with SCI learn strategies to maintain an upright position, e.g. use of the upper limbs to stabilise the trunk and long sitting (sitting with outstretched legs) to improve stability. Long sitting requires an appropriate length of the hamstring muscles (the muscles at the back side of the upper leg), which should be maintained by regular stretching exercises.. Depending on the level of injury, the ability to sit unsupported should be assessed and trained. Keep in mind the advices, on shifting position regularly while sitting in the wheelchair.





Long sitting

Card 21

Activities and participation

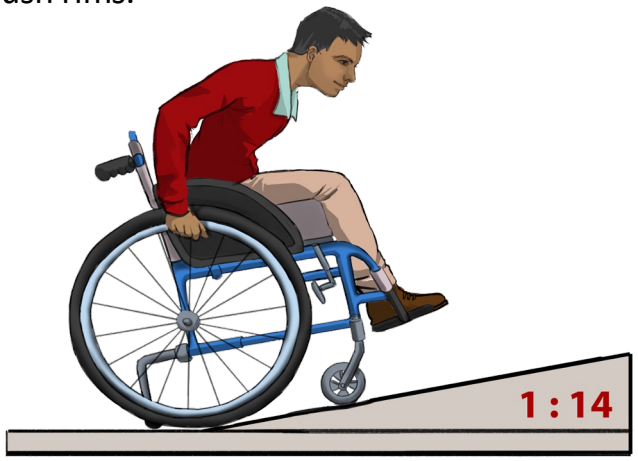
Wheelchair mobility

Many wheelchairs have been adapted to suit varying environment. People with SCI need to learn to propel the wheelchair with long, slow strokes, gripping the handrim as little as possible in order to let the wheelchair glide. The person will need to be safe and competent in moving with the use of a wheelchair across different terrains.

Slopes

The best way to **descend** a slope is to maintain a wheelstand while letting the push rims slide securely through the hands. For mild slopes it may be sufficient to roll gently with the upper body held backwards in order to avoid tumbling over.

For **ascending slopes** the person should be leaning forward while making short, powerful strokes on the push rims.



Wheelstand

Balancing on the rear wheels (wheelstand) is an advanced wheelchair skill. This is necessary to lift the front wheels over obstacles, descend over steep slopes, turn in tight places and move on rough terrain.

How to make a wheelstand

1. Make a strong, short push forwards to generate sufficient momentum on the front wheels to lift.
2. Lean backwards while pushing forwards on the wheels. This is a subtle movement that requires sufficient upper body control.

NOTE: As there is the risk of tumbling over backwards, this requires a lot of practice. Never practice without support from another person. Persons with SCI should use anti-tip bars that prevent tumbling on the wheelchair when not practising.



Card 22

Activities and participation

Steps

Moving over steps should be practiced with the support of another person or therapist until the person is secure enough to do it alone.

How to ascend (go up) a step

1. Make a wheelstand or briefly lift the front wheels 30 cm before the step.
2. As soon as the front wheels touch the step, push powerfully forwards to roll the rear wheels up onto the step.
3. If possible, lean quickly forward when the front wheels touch the step to create momentum.

Two methods to descend (go down) a step

1. Roll slowly backwards and lean forward as soon as the rear wheels roll over the edge of the step to prevent yourself tumbling over. This requires sufficient control over the upper body and is not advisable with high steps.
2. Make a wheelstand and move forward until the rear wheels are level with the edge of the step. Slowly let the wheels roll over the edge while maintaining a wheelstand. Lean forward when making the move, and NEVER let go of the push rims of the wheels!



Card 23

Activities and participation

Occupation

Occupations such as leisure, sports, work/income generating activities and parenting have strong social and psychological benefits. They can have a positive effect in regaining self-confidence while experiencing success and achievement. Adaptive sports such as wheelchair basketball, wheelchair rugby, sitting volleyball and swimming not only increase personal skills and independence, but also have a positive effect on physical and mental fitness.

Obstacles to participate can be found and addressed at different levels.

- The personal level: plan and prioritise social events, provide personal counselling or peer support.
- The interpersonal level: provide family counselling, encourage people to join a disabled people's organisation, sensitize the community.
- The physical level: ensure physical access , adapt the activity.





Card 24

Activities and participation





Vocational training, education, work

Persons with SCI should be enabled to continue their education or work as far as possible. They should continue their education, income-generating activities, with adaptations if necessary, or find other suitable work. They may need long-term guidance to find a vocation that matches their interests and abilities.

Actions to take

- Together with the person with SCI and family:
    - Return to work or school: obstacles and how could it be adapted?
        - Transportation to school or work
        - Accessibility of the facilities, including toilets
        - Attitude of colleagues, boss, teachers and other students
        - Mediate conditions and test it for a certain period of time (job profile, working hours etc)
    - If return to the previous work is not possible: what could be a suitable income-generating activity and what new skills and knowledge are needed for this?
        - What are the study support and job placement opportunities
        - Identify resources for access to scholarships or other entitlements. Families of persons with SCI often face more financial challenges than usual.
    - Do they have an appropriate wheelchair in which they can comfortably function throughout the day and, when needed, additional assistive devices that enable their functioning.
    - Sensitize teachers, trainers and employers to the special needs of the person with SCI.







Personal factors:
Information and
Actions to take







Card 25

Personal Factors

Personal feelings

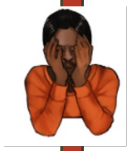
Acquiring a spinal cord injury is a life-changing event for both the affected person and their family. The person with SCI often has strong feelings of loss of control and autonomy.
They will most likely ask themselves why this misfortune overtook them. For these sort of questions, they may benefit from consultation with a religious leader – a priest, a pastor, an imam, a rabbi- or from partaking in religious rituals. It is good to be aware that not only practical support is needed but also spiritual support.

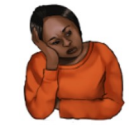
NOTE: Depression affects 40% of SCI patients. Depression is an illness characterized by persistent sadness and a loss of interest in activities once enjoyed, accompanied by an inability to carry out daily activities that lasts for at least two weeks. It can lead to a variety of emotional and physical problems, such as a loss of energy, a change in appetite, sleeping more or less, feelings of worthlessness and thoughts of self-harm or suicide. If this last occurs, refer to a specialist! Refer to a psychologist if needed and available if you suspect persistent depression.

Each individual has unique coping strategies and reactions, which may well change over the course of adjusting to a life with a disability.

Actions to take

- Getting information about the process and prospects helps the person to adjust.
- Being involved in learning to taking care of oneself will help to feel to be in control.
- Encourage and support the person to return to work/school and previous roles in life and discuss what adaptations will be needed.
- Connect with peers with SCI.









Acceptance phases

The person with SCI usually passes through different acceptance phases. It is important for the fieldworker as well as the family to be aware of them.

Denial phase: denial of the situation characterised by refusing to face the reality of the accident or the effects of a certain disease. Give room to the person to express their feelings.

Negotiation phase: during this phase people hope that a miracle will occur. It is important not to comfort the person too much because it will result in the person staying longer in denial or negotiation phase.

Anger phase: once people realise that it is impossible to change the condition, they usually blame it on unfairness of life. They get angry at people around them; people who take care of them, doctors and health staff, even at themselves. Be aware that this is a necessary phase, try to keep calm and highlight the future opportunities.

Acceptance phase: it can take up to one or two years after the SCI injury to reach this phase. However, some people do not reach this phase and cannot accept their new life situation after SCI.
In the long run, the majority of people with SCI adjust well to life with an injury. Satisfaction in life after SCI is associated with employment, income, a low frequency of medical complications, and having social opportunities. For positive adjustment to take place, the person with SCI and his/her family will need practical and mental support for several months or even years. Each individual has unique reactions and coping strategies after such traumatic experience.

Changed roles

Depending on the cultural context the impact of having a SCI can be different for a man and for a woman. Not only for the person with SCI, but also for the partner of the person with SCI. The role of the partner or family members can change, with adding a new role of being the personal assistant.

The family also goes through the adjustment phases. Also, recognize that they may experience revulsion, the need for escape, fear of ongoing economic dependency. For husband or wife there may be loss of sexual arousal. If the personal assistant is a family member or in a relationship with the person with SCI, attention should be paid to issues of personal space and intimacy to avoid the caregiving affecting the relationship in a negative way.

Possible interventions include the following.

- Listen to the concerns of the person and provide information about what the person can do and what the prospects are.
- Discuss the expectations of the person and the family members towards each other.
- Facilitate cooperation in adjusting to the new situation at home.
- Refer to psychologist if needed and available
- Whenever possible, encourage the person to return to work/school and continue taking on previous roles in life. Discuss together with the person and with the family what is needed to make this possible.

Sexuality

A SCI almost always changes sexual functioning due to loss of physical function, sensitivity, incontinence, spasticity or pain . But the capacity for sexual thoughts and desires remains. Having a satisfying intimate life doesn't always require having sexual intercourse; it can be found in many other ways. Most important may be to maintain open communication between the partners and to explore other forms of intimacy and stimulation if needed.
It often requires a lot of courage for people with SCI to express their sexual concerns with somebody they trust. A skilled counsellor may be able to facilitate communication between partners and advise on possible body positions, the use of medication and/or stimulating tools.
NOTE: While men with SCI may have limited fertility, women remain fertile. Pregnancy can still occur. Remember that a SCI will not protect the person from contracting sexually transmitted diseases, so precautions should be taken just as much as others do or should do!

Peer counselling

Peer counselling consists of emotional and practical support provided by people in similar situations, i.e. other persons with SCI and/or their caregivers. Peer counselling can be a valuable asset to a person with a recently acquired SCI, especially when support is provided by someone with SCI. Peers can answer questions on how to maintain personal relationships and build new ones. Peer support can be directed at the individual person with SCI as a "buddy", but also at caregivers in the form of family counselling , or as group counselling.
Persons with SCI can need peer counselling but can become later peer counsellor for others as well.

Always refer to a OPD (Organisation of People with Disabilities) or SHG (Self Help Group) for people with (physical) disabilities!











Environmental factors:

Information and

Actions to take





Card 27

Environmental Factors

Independent living in the community

Persons with SCI have the same right to participate in society as others. To foster people's participation in society, efforts have to be made to achieve the following:

- Change family and community attitudes by counselling and awareness raising.
- Make the physical environment, transportation and information accessible to all persons with disabilities. Access to health service is very important for the person with SCI. But being able to go the the market may be as essential.
- Abolish discriminatory laws and regulations and foster enabling policies and practices.
- Ensure, if needed, access to personal assistance and/or community based services.





The personal plays a crucial role in improving and maintaining their quality of life and may be

- a person outside the family, who is paid for the assistance
- the partner of the person with SCI
- a family member or friend
- different personal assistants who take turns

If the personal assistant is a family member or partner, attention should be paid to issues of personal space and intimacy to avoid the caregiving affecting the relationship in a negative way.

Fieldworkers can play a crucial role in supporting, counselling the person and family members and referring to the appropriate services and advice in making the house and environment accessible.

Actions to take

- Listen to all, and answer questions
- Discuss the (changed) roles within the family structure
- Refer if needed to other services, in collaboration with the family
- Stimulate a positive approach to the future
- Refer them to peer support groups
- Arrange trainings for the personal assistant if the person with SCI is not independent in daily activities.

Card 28

Environmental Factors

Transport

The ability to make use of private or public transport depends largely on the ability to make wheelchair-vehicle transfers , the ability to fold the wheelchair and the willingness of drivers to take the person on board. Without being able to make use of transport, participation is restricted and makes it difficult to go to work, school, visit friends, go to the marketplace and community activities, causing isolation.

The following measures should be carried out to facilitate the use of transport:

- Encourage the person with a SCI to carefully prepare before travelling, e.g. take precautions for bladder and bowel management.
- Explore opportunities within the environment for support, e.g. request relatives or friends for assistance to access public transport.
- Adjust privately owned vehicles to suit the needs, preferences and abilities of the person with a SCI, e.g. ask a car mechanic/technician to make necessary adaptations such as building hand controls.



Card 29

Environmental Factors

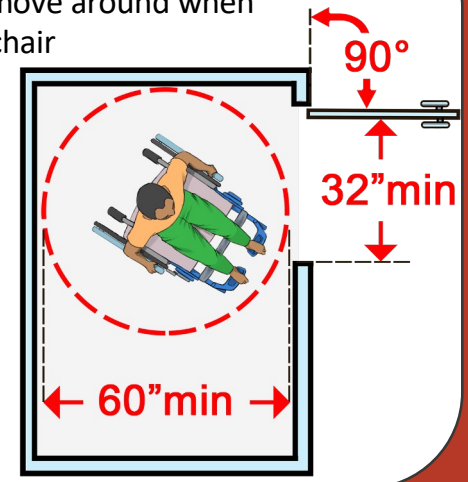
Moving outdoors

Inaccessible environments can make use of wheelchairs, walkers and crutches difficult. A bumpy road is not wheelchair-friendly, especially if the tires are thin, or the destination is simply too far. This may disrupt participation in the community. They may also experience stigma when being outside or wanting to use public transport.

A wheelchair with large wheels or a tri-bike can help move around in the community.



There should be enough space in the rooms to move around when using a wheelchair

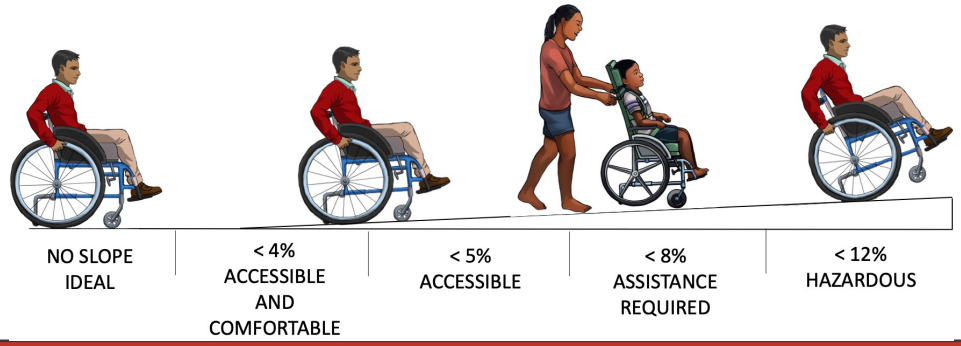


Home modifications

People with SCI using a wheelchair can be hesitant to adapt their home as it may affect family activities. With some creativity (and sensitivity), a lot can be modified to achieve temporary or permanent solutions.

Possibilities for home modifications

- Establish ramps where there are steps. The international standard for slopes is 1:14. This means that for every 14 centimetres travelled horizontally, the ramp rises 1 centimetre.
- Ensure sufficient turning space (minimum of 60 inches) for the wheelchair user to rotate on the spot.
- Doorways should be wide enough (minimum of 32 inches with the door open to 90 degrees) to pass with the wheelchair and doors light enough to open and close from within the wheelchair.
- Tables and kitchen sink should preferably be wheelchair accessible and cupboards within reach of the wheelchair user.



Card 30

Environmental Factors

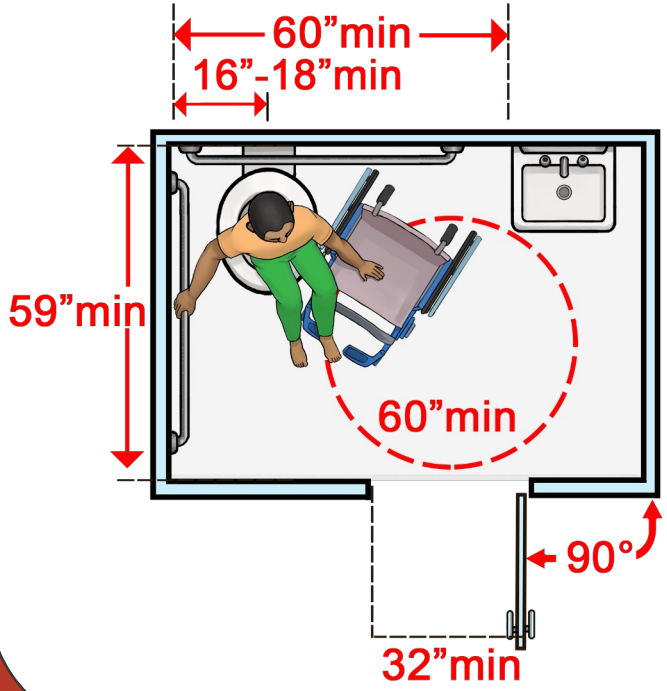
Bathroom modifications

There are about 4 options when making a bathroom/toilet suitable for a person with SCI.

1. If the person is able to make transfers to the toilet or commode independently, the following are important:
    a. Have sufficient space (minimum of 59 inches) in front of the toilet/commode for a safe transfer. And between the sink and the wall (minimum of 60 inches).
    b. Level the toilet/commode where possible to align with the height of the wheelchair.
    c. Install grab rails alongside and behind the toilet.
    d. Have padded toilet seats as bowel routines can take long.
2. If the person uses a mobile shower commode for toileting and showering, ensure the following:
    a. Have sufficient space in front of and next to the toilet to be able to manoeuvre the commode over the toilet (minimum of 16 to 18 inches between toilet and wall).
    b. Have sufficient space on the open side for a carer when assistance is needed (minimum of 60 inches wheelchair rotation space).
    c. Have the toilet low enough for the commode to fit over it.
3. The mobile shower commode can also be used with a pan or bucket when the toilet is not accessible.
4. In high-level injuries or in the period shortly after the injury, all bathroom activities may need to be performed with assistance.

NOTE: Always ensure that when the person's abilities for self-care during the rehabilitation phase increase, the bathroom and/or toilet are adapted to a reasonable extent to enable independent functioning. In all cases, maintain optimal hygiene as this can prevent complications. Use tiles and surfaces that can easily be cleaned after each routine if possible.



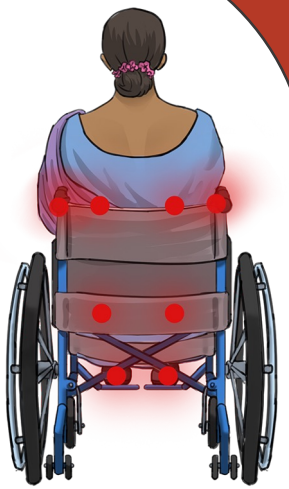


Card 31

Environmental Factors

Wheelchair seating





Wheelchairs can be passive (pushed by another person), manual, or motorised. Seating on all wheelchairs should be optimal so as to prevent skin problems, maintain posture and enhance independent mobility and functioning.
A wheelchair is considered appropriate if it:

a. meets the individual's needs and environmental conditions;
b. can be obtained and maintained in the country at an affordable cost;
c. provides mobility;
d. and increases independence.

People with SCI often spend many hours in the sitting position, therefore take the following issues into consideration:

- Avoid pressure points (especially under the buttocks), folds in clothing and sliding forces to prevent pressure sores .
- Depending on availability and preferences, foam cushions, gel cushions or air cushions can be used in the wheelchair. They should fit the wheelchair well, and be removable and easy to clean.





NOTE**:** No specific cushion, or adjusted wheelchair, can be as effective in preventing pressure sores as regularly changing body postures and applying pressure relief techniques! Consult a (occupational) therapist for assessment and measurement!

Colophon

For the development of the SCI chapter of the RehApp, we acknowledge the International Spinal Cord Society - ISCoS - (hyperlink to: http://www.iscos.org.uk/) and elearnsci.org (hyperlink) as a valuable source of information on SCI for medical and paramedical professionals. We highly recommend following one of their online learning modules on www.elearnsci.org (hyperlink). A module for persons with SCI and carers is anticipated. Also, many thanks to Eric Weerts from Humanity & Inclusion and Wouter De Groote for providing input on the content of this chapter.

We would especially like to thank Nyna Bot and Yohanes Hastadi Kurniawan for taking the photographs in Yogyakarta Indonesia. We thank Pusat Rehabilitasi Yakkum - PRY Indonesia - for their generous support in developing and testing the app and the Centre for the Rehabilitation of the Paralysed (CRP) Bangladesh for providing feedback on the field trial.

For further reading we recommend consulting the following resources:
The website of the International Network of Spinal Cord Injury Physiotherapists (SCIPT hyperlink to http://www.scipt.org/) with free access to a number of valuable presentations and documents.
The book Back on Track, Spinal Injury Rehabilitation Handbook (hyperlink to https://www.google.com/url?hl=en&q=https://nzspinaltrust.org.nz/resources/back-on-track&source=gmail&ust=1482245259342000&usg=AFQjCNHfnW4HVKyjGSDoc-ofmNj-qu6yDA) from the New Zealand Spinal Trust, also available as e-book, CD-ROM and DVD.

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