

An tOspidéal Náisiúnta Athshlánúcháin

Physical Care After Spinal Cord Injury

Booklet 5



Physical care after Spinal Cord Injury

This is one of a series of booklets developed by the Spinal Cord System of Care (SCSC) Team at the NRH.

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Introduction

This booklet describes useful exercises for some of the most common physical consequences of spinal cord injury including tone or spasticity, shoulder and arm problems, neuropathic (nerve) pain and fatigue. While you may not experience all of these, you are strongly advised to make physical exercise part of your weekly routine.

The importance of exercise

Engaging in physical activity is very important for your health, independence and quality of life after a spinal cord injury. It helps to improve your breathing, muscle strength, circulation, body composition, self-esteem and self-confidence.

Physical activity helps to reduce your risk of heart disease, pain, depression, and anxiety. Sports and fitness activities also provides social interaction and can become a real interest or hobby after discharge from hospital. During your rehabilitation at the NRH, you will attend physiotherapy as part of your programme, and have the opportunity to explore different exercise options best suited to your level of ability.



What types of exercise should I do after my SCI?

You need to do a variety of exercises because they are all important in different ways. Your physiotherapist will work with you to find a balance of the following exercises:

- **Strengthening:** for building muscle and becoming stronger. This is important for functional activities such as transfers (moving to and from your bed, wheelchair or car). Training can be carried out using body weight, free weights, resistance bands and weight machines.
- Aerobic exercise: for improving fitness and heart health. It can also help to manage fatigue and pain over time. Exercises include, but are not limited to, wheeling your wheelchair, walking, cycling and various sports such as football, wheelchair basketball, tennis.
- Cardiometabolic health: for helping to maintain a healthy weight, keeping your heart healthy and reducing the risk of diabetes, provided you also eat well. These are the same exercises as aerobic or fitness exercises but must be done for longer and more frequently.

Current guidelines for adults with Spinal Cord Injury (SCI) recommend doing both aerobic activity and strength training at least twice a week.

Aerobic activity: 20 minutes of moderate to vigorous intensity exercises. This does not include a 5-minute warm up and a 5-minute cool down.

Strength training: 3 sets (8-10 repetitions) of moderate to vigorous intensity exercises for each major muscle group. Don't forget to warm up before these too.

Cardiometabolic health: 30 mins of moderate to vigorous intensity aerobic exercise at least 3 times a week.

Doing more than these recommendations will give you extra fitness and strength benefits. However, if you cannot reach the amount of exercise in these guidelines, then doing some activity is better than doing nothing at all!

Top Tips

- Pick an exercise or activity that you enjoy it does not have to be a sport or going to the gym. Pushing your wheelchair, walking, gardening, cycling and swimming are all good exercises.
- Pick a regular time and day of the week for exercise. This helps build good habits.
- Use a diary to keep a record of the exercises you do every week.
- Exercise with someone else or as part of a club for extra motivation.
- Make sure you perform any exercise with the correct technique 'quality over quantity' is important.
- Be careful not to over exercise one area of your body (particularly in your strength training). Your physiotherapist can advise you on this.





Sports and exercise after discharge

There are many organisations that support people with spinal cord injury to get, or to stay, involved in sport, fitness and physical activity after rehabilitation. These include your local sport inclusion and disability officers (SIDO) and the Irish Wheelchair Association (IWA). Your treating team can help you find these services.



Tone and Spasticity

What is spasticity?

During rehabilitation, your treating team may talk about the tone or spasticity in your muscles. Muscle tone describes how your muscles feel when your joints are moved. Normally, this should be easy to do and there should be no stiffness. However, with a spinal cord injury, the muscles can feel stiff and a bit more difficult to move. Spasticity may also be described as increased muscle tone.

Spasticity is abnormal muscle stiffness or over-activity in a group, or groups, of muscles. This over-activity in the muscle is due to a disturbance in the messages going to or from the brain through the spinal cord due to injury or disease. About 70% of people who have a spinal cord injury have some spasticity.

Spasticity can cause:

- Muscle tightness or shortening
- Difficulty in movement and therefore in doing practical tasks.
- Muscle tiredness
- Pain
- Fatigue
- Breathlessness if spasticity is in the trunk
- Difficulty with hygiene of affected area

However, it is important to remember that some spasticity can be useful and can help with function, for example, transfers. Your physiotherapist can advise you about which spasticity is helpful.

Types of spasticity

Flexor spasticity:

Your limb bends upwards towards your body.

Extensor spasticty:

Your limb extends away from your body.

Adductor spasticity:

Your limb will pull inwards towards your body. Mostly this is experienced as difficulty separating your thighs.

Spasticity affecting the trunk:

Your back or trunk will arch off a bed or away from the back of a chair.

You can also have a mix of flexor and extensor spasticity.





What makes spasticity worse?

Many things can influence spasticity. A trigger is a sensation or stimulus in your body that makes your spasticity worse. Being able to identify these triggers and manage them is important. It is also important to note that a sudden change in spasticity could be a sign of underlying infection – if this happens, please speak to your medical team or GP.

Common triggers

- Bladder problems, for example, a blocked catheter or the bladder not emptying properly
- Bowel problems, such as constipation
- Skin problems such as pressure injuries
- An in-grown toenail
- Urinary tract infection (UTI), or other infections
- Pain and discomfort anywhere in the body
- Sudden movements or stretching too quickly
- Positioning, for example change of position or being poorly positioned in your wheelchair
- Excessive tiredness
- Extremes of temperature
- Strong emotions, stress and anxiety



How can I manage my spasticity?

While spasticity cannot be fully reversed, it can be managed well. Spasticity is managed using a mixture of different approaches including:

- Prevention of the common triggers listed above
- Positioning: this means getting into the best position possible in your wheelchair or in bed at night-time
- Splinting
- Medication which may include; baclofen, tizanidine, clonazepam, botulinum toxin and others.
- Standing: this includes a supported standing programme with equipment (Easy stand or tilt table).
- Stretching or lying on your stomach can be useful if advised by your therapist.
- Relaxation techniques

Your spasticity can get worse over time if it is not managed properly so it is important to keep using these strategies. Your treating team will advise you on what might work best for your level of injury or illness.



Standing Guidelines

The Multidisciplinary Association for Spinal Cord Injury Professionals (MASCIP) recommend that standing options for all patients with a spinal cord injury should be individually assessed. This should happen as soon as it is safe to do so after your spinal cord injury. Your physiotherapist will prescribe a standing programme for you, including the use of equipment to best meets your needs. After injury it may take many sessions before your body can tolerate being fully upright again. Different types of equipment such as a tilt table or *Easy Stand* may be used to support standing.

The benefits of standing include:

- Managing your spasticity or increased tone
- Helping your bladder and bowel
- Improving your blood circulation
- Helping your breathing
- Improving your wellbeing

Current evidence-based guidelines recommend that standing should take place 3 or more times a week for **30-60 minutes** each time.



Protecting Your Shoulders and Arms

For both complete and incomplete spinal cord injuries, the shoulders and arms play an important part in increasing independence. Shoulders and arms are very important for activities such as pushing a wheelchair, transfers and lifting a wheelchair in and out of a car. Walking with aids such as a frame, crutches or a stick also makes extra demands on your shoulders.

Many patients with new spinal cord injuries report some level of shoulder pain. It is also common to begin to experience pain after many years of living with a spinal cord injury. Pain can often develop due to muscle imbalance, overuse and degenerative changes (normal changes in the body as we age).

Sometimes, shoulder pain is **neuropathic** – this means that some of the pain is coming directly from the injured nerve cells in your spinal cord.

Important Muscle Groups

Recovery of muscle strength in your arms following a spinal cord injury may be a key goal during your rehabilitation. Your therapists will advise you on what muscles to target and how often to exercise them.

The muscles at the back of your shoulder and arm that are important for everyday tasks. Targeting these muscles, if possible, will assist you to prevent shoulder injury.

The Importance of Protecting your Arms and Shoulders

Protecting your arms and shoulders from the start is the best way to prevent problems developing later.

shoulder depressors

help with transfers, pressure relief

shoulder extensors

help with manual wheelchair propulsion





shoulder external rotators

help stabilize the shoulder to prevent pain and injury

shoulder retractors

important for posture and pulling motions





triceps

help with transfers, pressure reliefs and locking the elbow

Your Wheelchair

Some people with a spinal cord injury require a wheelchair for all their mobility. Your wheelchair will be individually prescribed based on a professional assessment. Lightweight wheelchairs are more suitable for full time wheelchair users but they may not suit everyone. Try to find the most efficient way of propelling your wheelchair to reduce the risk of injury to your shoulders. Using longer push strokes can reduce the number of pushes you need to make to move the chair. It also reduces the force needed to push the chair.

Try to minimise the need to travel over more difficult ground (steep areas, rough surfaces). You can also explore powered mobility and power assist options for your wheelchair. This can make it easier to get around (especially on uneven ground or hills) without increasing the demand on your arms.

Make sure your tyres are properly inflated. Low tyre pressure increases the friction between the tyre and the ground and increases the demand on your shoulders. If possible, take your wheelchair apart before lifting it into a car, or think about other options such as a rooftop hoist or installing a ramp in your car that minimises the need to lift your wheelchair at all.





Your Transfers

If you are completing sideways transfers, you should try to complete same level transfers as much as possible. Adjust your bed height to the same height as your wheelchair if possible. The height of your car seat may also need to be considered. The use of a transfer board allows smaller lifts which will reduce the amount of force needed to make a sideways movement.

Your physiotherapist and occupational therapist will help you improve your transfer technique during your rehabilitation. Leaning your body forward will reduce the amount of weight your arms will need to lift. Pushing your shoulder blades down as you lift is also important to help protect your shoulders. Try to limit the number of transfers that you have to do daily.



Walking

Some people with a spinal cord injury recover the ability to walk independently or with the use of an aid. If you require an aid to walk such as a frame, crutches or a stick, you will increase the strain on your shoulders and your wrist and hands. Strategies such as pacing, frequent rest breaks and good posture awareness can help prevent the long-term effects of strain from over-use.

Other ways of protecting your arms if you have a painful shoulder

- Using your less used, non-painful arm for basic tasks such as feeding, opening doors and so on.
- Leading with your uninjured arm during transfers until the acute pain settles down.
- Modifying your environment, for example moving your body close to something or using assistive devices such a grabber so you won't need to reach or move your shoulder as much.
- Asking for help with tasks that are causing you pain.

More tips

- Twinges and minor aches can occur and are normal after SCI. However, if these don't go away after a few days and you are concerned, contact your GP, community physiotherapist or the NRH liaison nurse.
- Mind the neck and shoulder blades also (with regular movements and stretches).
- In the case of acute strains; heat treatments, ice, dry needling, or soft tissue massage can help.



Managing Fatigue

Fatigue can be defined as extreme tiredness after mental or physical exertion or as a result of an illness or injury such as a spinal cord injury. It can feel like a lack of energy, weakness or being too tired to take part in activities. It is different from 'drowsiness' which is linked with the need to sleep.

People with spinal cord injury describe physical fatigue (weakness, difficulty maintaining good posture or position); emotional fatigue (frustration and stress); and cognitive fatigue (sense of being overwhelmed) as aspects of their experience of fatigue.

Factors commonly associated with fatigue include, but are not limited to, pain, poor quality sleep, spasticity, poor diet, poor memory, and reduced concentration. Fatigue can sometimes hide low mood or depression. Be aware of any stresses or emotional issues, as well as physical ones, that may be causing you to feel fatigue.



Managing Fatigue

There are many strategies that may help you manage fatigue. During rehabilitation your treating team can offer support and advice on specific strategies that may help. General tips to help manage fatigue include:

- **Pacing:** It takes time to learn how to manage your time and energy following an injury. Pacing means doing things at a steady or planned rate, rather than in bursts. It allows you to save energy and prioritise tasks that are important to you.
- **Exercise:** While exercise can contribute to fatigue, it also helps to build up your ability to deal with it.
- **Try to eat well:** Eat a balanced diet and try not to skip meals.
- Manage your workload and stress levels: keeping your workload at a steady level from day to day helps to reduce stress. Set small goals and prioritise tasks.
- Plan rest times: Modify daily activities to build in rest periods. Give your brain a rest by taking 'time-out' from concentrating. This could mean sitting quietly, listening to music or practicing relaxation or mindfulness activities.
- Avoid napping: Napping can disrupt your sleeping routine. If you need a nap, limit it to 20-30 minutes and avoid napping after 3pm.
- Be aware of what you can and cannot do and ask for help when needed.
- Engage in meaningful, enjoyable and rewarding activities.



Sleep

One in four people experience sleep difficulties at some point in their lives. These include having trouble falling asleep, trouble staying asleep, early morning waking, sleeping too much, or restless or unsatisfying sleep. Sleep is important for your mental wellbeing. Sleep difficulties can affect your mood. Factors such as pain, anxiety and low mood can also affect your sleep.

Some Barriers to Sleep

- **Pain:** If pain disrupts your sleep, ask your medical team about the best time to take medications in order to provide the best possible pain-relief throughout the night.
- Medication: Some medications, and some herbal remedies, have side effects linked to insomnia. Be sure to read the instructions for all your medications and consult your doctor or pharmacist if needed.
- **Alcohol:** Alcohol disrupts the quality of your sleep and makes you feel less refreshed even after a full nights sleep.



Sleep Hygiene

'Sleep hygiene' is the term used to describe helpful sleep habits. Lots of evidence shows that using the following tips for regular, positive daytime and bedtime routines can help you to sleep better.

- Exercise: People who engage in some form of regular physical exercise every day tend to have more restful sleep. The best time to exercise is in the late afternoon or early evening. Exercising in the morning, while good for you, will not help with sleep. Exercising less than two hours before bedtime can interfere with sleep.
- Regularity: Having a regular bedtime routine helps to train your body to wind down and know it is 'bedtime'. Most adults need between 7 and 9 hours of sleep a night. Try to avoid catching up on sleep after a bad night, as activities such as 'lie-ins' and napping can sometimes disrupt your sleep routine.
- Naps: If you must nap, limit it to 20 minutes early in the day. Try to have a regular morning routine too. Get up at the same time every day (even weekends).

- Wind down: Take time to relax and create a routine before you go to bed. Have a warm bath, write a 'to-do' list to clear your mind, or read a book. Consider doing some relaxation exercises or meditation to help you to wind down. Do this consistently so that your body and mind begin to associate this process with going to sleep.
- Eat well: Eat plenty of fruit and vegetables and avoid heavy food or big meals within 2 hours of bedtime. Limit alcohol and caffeine before sleeping. Alcohol disturbs your sleep and makes you feel less refreshed in the morning. Try warm, milky or decaffeinated drinks instead. Limit liquids in the evening before going to bed if you find yourself waking up to use the bathroom.
- Create a good space for sleep: Keep your room dark, tidy, quiet, relaxed and at a comfortable temperature. Try to avoid watching television, working, or studying in bed, because these activities keep your mind active, which gets in the way of sleep. Avoid using smartphones or electronic devices an hour before bed. Screens give out light that stops the release of melatonin, a hormone that helps you sleep. Keep your room free of clutter and minimise disruptions such as sound and light by using earplugs or blackout blinds.
- Keep a sleep diary: This can help you to find lifestyle habits or activities that relate to sleep problems (such as caffeine consumption, activity levels). A sleep diary could also reveal any underlying health conditions that contribute to insomnia and can be given to your GP, if sleep problems persist or worsen.

Remember

- Start small: Making small changes can have a large impact on your sleep. You don't have to try to do everything all at once. Instead, pick one or two strategies and try them. When you're ready (and if you need to), try adding a new strategy. The goal is to slowly start increasing behaviours that can help you sleep, while reducing the things that interfere with your sleep.
- **Be consistent:** Pick a strategy and use it consistently. Try to do the same thing every night for a few weeks or a couple of months.
- **Be patient:** These strategies can take time to improve your sleep. In fact, sometimes things can get slightly worse before they get better (for example, because you may no longer be napping). Try to stick with any changes you make for long enough to make a difference.

Neuropathic Pain

Neuropathic or nerve pain is common after a SCI. It is one of the most distressing consequences of a spinal cord injury. Neuropathic pain can start soon after the onset of injury or develop later. It can affect part of a limb, a whole limb or much larger areas of the body.

Sometimes it can feel like a band around your body especially in people with a spinal cord injury in the thoracic area. This is what we sometimes call 'at level neuropathic pain'.

Sometimes the pain can occur throughout your lower body and this is called 'below level neuropathic pain'.

People describe nerve pain as "burning", "like a toothache", "like an electric shock", "more of an uncomfortable sensation than a pain". For some people, the pain comes and goes, for others it is constant.

Some people find that certain things trigger their pain such as cold weather, a urinary tract infection or constipation. Some people use physical strategies to help reduce pain, such as using a standing frame or playing a sport.

Strategies that may help you to manage neuropathic pain:

 Regular exercise, when used with other strategies, helps maintain flexibility and movement. Exercise can directly help relieve inflammation and stiffness that can cause pain. Aerobic exercise like cycling, walking and some sports also encourages the body to produce its own pain-relieving chemicals. Try to balance aerobic exercise with strengthening and stretching. You may get a mild flare up of pain when first starting to exercise. This is normal and not a sign that you are doing further damage.

The diagram below shows how fear of doing more harm can prevent people taking exercise which then leads to more stiffness and more pain. Exercising, despite the pain, can lead to increased strength, ability and self-management which can produce a feeling of relief.



Other strategies that may help you to manage neuropathic pain:

- Transcutaneous Electrical Stimulation (TENS) is a form of electrical stimulation which can help trigger the body's own pain relief systems. It is applied using electrode stickers placed on the skin.
- Medications can be used to help with neuropathic pain. However, they are not always effective for neuropathic pain and may have side effects. Some of the commonly used medications are gabapentin, pregabalin, amitriptyline.
- Psychological strategies, including distraction, goal setting, relaxation and challenging negative thinking can also be very helpful. Psychological strategies for managing pain are described in the 'Psychological Wellbeing After Spinal Cord Injury' booklet.

One of the most effective treatments for pain is a pain management programme made up of many elements for example, a physical programme including stretching and aerobic exercise, cognitive behavioural therapy, education about pain, and relaxation strategies.

You can develop a personal pain self-management plan with the support of your NRH team. Everyone's pain is different and therefore what people find helpful to manage pain will also differ. People living with neuropathic pain and spinal cord injury for a long time report that distraction is one of the best treatments for their pain – in other words, engaging as much as possible in a range of normal life activities including family life, work and recreation.

Common Terms

Aerobic exercise: Examples include walking, running, pushing your wheelchair, swimming, cycling or hand cycling, sports such as basketball, tennis, rugby and hockey.

Cardiometabolic exercise: Same as aerobic exercises except you need to do them more often and for a longer duration.

Insomnia: A common sleep disorder that can make it hard to fall asleep or to stay asleep. It can also cause you to wake up too early and not be able to get back to sleep.

Major muscle groups: Muscles in your arms, legs and trunk that support basic movement.

Moderate intensity: Exercise that requires a moderate amount of effort and noticeably increases the heart rate. You should be able to talk but not sing.

Neuropathic pain: Neuropathic pain is caused by damage or injury to the nervous system. Symptoms can range from mild to severe. The pain is often described as burning, like an electric shock or like a toothache.

Sideways or lateral transfer: This is a method of moving from one surface to another (such as wheelchair to bed and vice versa) using your arms and body to lift your hips across. You do not need to use your legs to do this transfer. People often use a transfer board to bridge the gap between the two surfaces.

Sleep hygiene: Sleep hygiene means 'cleaning up' sleep habits that interfere with sleep.

Spasticity: Often referred to as increased tone or stiffness in the muscles, making it more difficult for someone to move your joints.

Splinting: Use of a rigid or flexible device to maintain a body part in a certain position such as keeping your knee straight



Strengthening exercise: Examples include using arm or leg weight machines in the gym, lifting free weights or a bar bell, doing squats, lunges, push-ups or pilates.

Thoracic: The longest part of the spine going from the base of the neck to the mid-lower part of the back.

Tone: How your muscles feel when someone moves your joints.

Vigorous intensity: Exercise that requires a large amount of effort causing fast breathing and a large increase in the heart rate. You should not be able to say more than a few words before needing to take a breath.

Frequently Asked Questions

Can I over-exercise?

Going above recommended exercise guidelines can give you further strength and fitness gains. However, it is also important that you balance how much exercise you do with your daily activities and rest periods. You should always gradually build up your level of exercise. Your physiotherapist will be able to support you in building an exercise programme that is tailored for you.

How can physiotherapy help my spasticity?

In one word, movement. Your physiotherapist will design a programme best suited to your level of spasticity. This might include stretching, positioning in your bed and wheelchair, a standing programme and splinting.

What equipment is available to prevent a shoulder over-use injury?

There are lots of different types of equipment which will help reduce your risk of an over-use shoulder injury. These include using a board for sideways transfers and powerchairs or power assist options for your wheelchair. Your physiotherapist and occupational therapist will advise you on what might work best for your injury level.

Why am I being referred to the Wheelchair and Seating clinic?

Your physiotherapist will refer you to the NRH Wheelchair and Seating clinic if they have assessed that there is a need for a wheelchair. This does not always mean you need a wheelchair full time. It may be to help you get around over longer distances and access your community environment.

Is a powerchair a good option for me?

Powerchairs can make getting around your local community much easier and often, faster. There are lots of different types of power assist options that you can explore with your occupational therapist and physiotherapist.



My Spinal Cord Injury

It is recommended that you design an exercise programme with your physiotherapists and other members of your treating team during your rehabilitation.

Exercises recommended for my level of injury include:

Contact details for: The Spinal Cord System of Care Programme

Administration: (01) 235 5145 (01) 235 5528 (01) 235 5537



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