



Living with a  
**Spinal Cord Injury**

Information after a  
**Spinal Cord Injury**

Queen Elizabeth National Spinal  
Injuries Unit

Queen Elizabeth University Hospital  
1345 Govan Road,  
Glasgow G51 4TF

Telephone: **0141 201 2555**

Website: [www.spinalunit.scot.nhs.uk](http://www.spinalunit.scot.nhs.uk)

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## Section 1

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## Personal Information

<b>Name:</b>	
<b>Level of injury:</b>	
<b>Cause of injury:</b>	
<b>Medical History:</b>	
<b>Allergies:</b>	

## Contact Telephone Numbers

### Hospital Team

Your consultant is: \_\_\_\_\_

Consultant's secretary's  
telephone number: \_\_\_\_\_

Your key worker is: \_\_\_\_\_

	Telephone Number:
Edenhall Ward Senior Charge Nurse	<b>0141 201 2533 or 2534</b> <b>0141 201 2535</b>
Philipshill Ward (Rehabilitation) Senior Charge Nurse	<b>0141 2530 or 2531</b> <b>0141 201 2532</b>
Spinal Outpatient Department Senior Charge Nurse	<b>0141 201 2563</b> <b>0141 201 2563</b>
Outpatient Appointments	<b>0141 201 2537</b>
Spinal Nurse Specialists	<b>0141 201 2550 or 2540</b>
Physiotherapy Department	<b>0141 201 2539</b>
Occupational Therapy Department	<b>0141 201 2553</b>
Clinical Psychologist	<b>0141 201 2547</b>
Education Sister	<b>0141 201 2543</b>

## Community team

	<b>Telephone Number:</b>
GP	
District Nurse	
Wheelchair Service	
Community Occupational Therapist	
Social Worker or Care Manager	
Other	
Other	
Other	

## Introduction to the

# Queen Elizabeth National Spinal Injuries Unit

This booklet is to give you and your family some key information about your spinal cord injury.

In the early stages after injury, it can often be difficult to take on new information. We do not expect you to learn everything that is in this booklet, but with time, you may find it a useful resource.

We would encourage you and your family to read through the booklet to familiarise yourselves with some of the issues relating to your spinal cord injury.

While this booklet will try to answer many of the questions you may have about spinal cord injury, there may be some issues that are not addressed. If you have any questions about your spinal cord injury please ask the staff.

The Unit has two wards: Edenhall and Philipshill as well as an outpatient department.

During your stay you will meet several members of the ward team. This includes:

- Medical Staff
- Nursing Staff
- Physiotherapists
- Occupational Therapists
- Clinical Psychologists
- Community Liaison Nurses
- Dietitians
- Education Sister

## Edenhall

We admit all new patients to this 12 bed high dependency ward. The priority is to medically stabilise patients.

There are more nurses in this ward as this is a specialised ward.



You will have a medical consultant and they monitor you throughout your stay. Your consultant will meet with you and your family to discuss your situation. You will also be able to speak with your consultant at any point during your stay in the unit.

Some people need medical machinery to help them in the very early stages. Some may need breathing support. This can often be quite daunting but please ask the staff to explain what the machines are doing.

### The first few weeks

When we damage the spine, we tend to have fractured the bones in the back. The doctors may decide to let the bones heal by themselves. This often means being on bed rest. People can be on bed rest for up to 12 weeks but the exact length of time depends on the nature of the fractures.

Whilst on bed rest, you will need nursing support to manage your bodily functions such as bowel and bladder function. With time, you will require less support and many will regain independence.

The length of stay in Edenhall depends on medical factors and whether you are ready for rehabilitation.

### Medical Staff

The Unit has 3 spinal injury consultants:

- Dr McLean
- Mr Fraser
- Dr Purcell

The unit also has a specialist in spinal injury, Dr Jigajinni.

You will have a named Consultant overseeing your care while in the unit. If they are not in the unit on a particular day, one of the other consultants will look after you.

The unit also has a range of other doctors, neurosurgeons, and specialists.

## Ward Rounds

While on Edenhall, you will see the doctors twice a day during the ward rounds. These happen at 9 am and 4 pm.

The main aim of the ward round is to monitor your health and make sure you are making progress.

There are larger ward rounds on Mondays which let the whole rehabilitation team evaluate and discuss your progress. There may be up to 11 people in these rounds.

The rehabilitation team will discuss a range of issues while at your bedside. While the ward round only spends a brief time with you, your consultant will offer a summary of what has been discussed with the rehab team and tell you of any new plans.

You can discuss any concerns with the doctors during the ward rounds or you can arrange a separate time to meet with your consultant.

## Moving from Edenhall to Philipshill

When you are ready we will move you from Edenhall to Philipshill Ward. We will plan this move in advance and discuss this with you and your family. In some cases we may have to move you quickly due to other emergency admissions but we try to avoid this.

It is common to be stressed at this stage in your recovery and the thought of further change can be unsettling.

## Philipshill and Rehabilitation

Rehabilitation is a process that you go through to regain maximum independence. On average, patients are in rehabilitation for 4 months. However, this may vary from 1 month to 9 months depending on your circumstances.

We hold Goal Planning Meetings approximately every 4 weeks to review your progress and set new goals. You will attend these goal planning meetings with your rehabilitation team, and your family are welcome to attend too.

By this stage the focus moves from medical stabilisation to rehabilitation, therefore your consultant may not attend these meetings.

### Rehabilitation Staff

During your time in rehabilitation, you will spend many hours working with physiotherapists and occupational therapists as you gradually increase your independence.

At this stage, you will start to become more independent, therefore, the nurses will encourage you to do more everyday activities on your own.

It is also the norm to meet with the clinical psychologist during your stay. As well as focusing on your physical recovery, it is important to acknowledge how you feel emotionally.

Your family can also meet with the psychologist as it is very common for them to experience emotional distress at this time.

### Any questions



Please remember that if you have any questions please ask the staff.

# The Anatomy of Spinal Cord Injury (SCI)

## What is the Spinal Cord?

The spinal cord is that part of your central nervous system that transmits messages between your brain and your body. The spinal cord has two major nerve pathways that help your brain control your body:

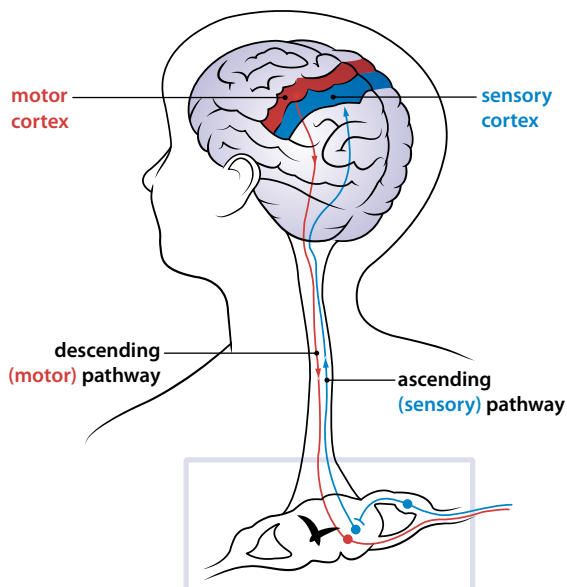
### 1. Motor Nerve (descending) Pathway

This carries information from the brain downwards to initiate movement and control body functions. This is coloured red in the diagram. Any damage to the motor nerve pathways, within the spinal cord, will result in the brain not being able to initiate movement and control within the body below the damaged site. This is known as paralysis.

### 2. Sensory Nerve (ascending) Pathway

This carries sensory information from the body upwards to the brain such as touch, skin temperature and pain. This is coloured blue in the diagram. If the sensory nerve pathways are also damaged then the brain cannot feel the body below the damaged area.

Major Nerve Pathways of the Spinal Cord



The spinal cord resembles a cable which is about the thickness of your little finger and is approximately 52 cm long. It begins at the base of the brain and runs down the length of the back ending behind the 1st lumbar vertebra.

Like the brain, the spinal cord is a very delicate structure and can be easily damaged by trauma. To protect them from the risks of everyday life, the brain is protected by the skull and the spinal cord by the spinal column. However for everyday activities we need our spine to be very flexible, allowing twisting and bending to occur.

This is possible, by the spinal column being made up of 33 individual bones called vertebrae and 31 pairs of nerves.

**Cervical** 7 vertebrae and 8 pairs of nerves that serve the arms

**Thorax** 12 vertebrae and 12 pairs of nerves that serve the torso

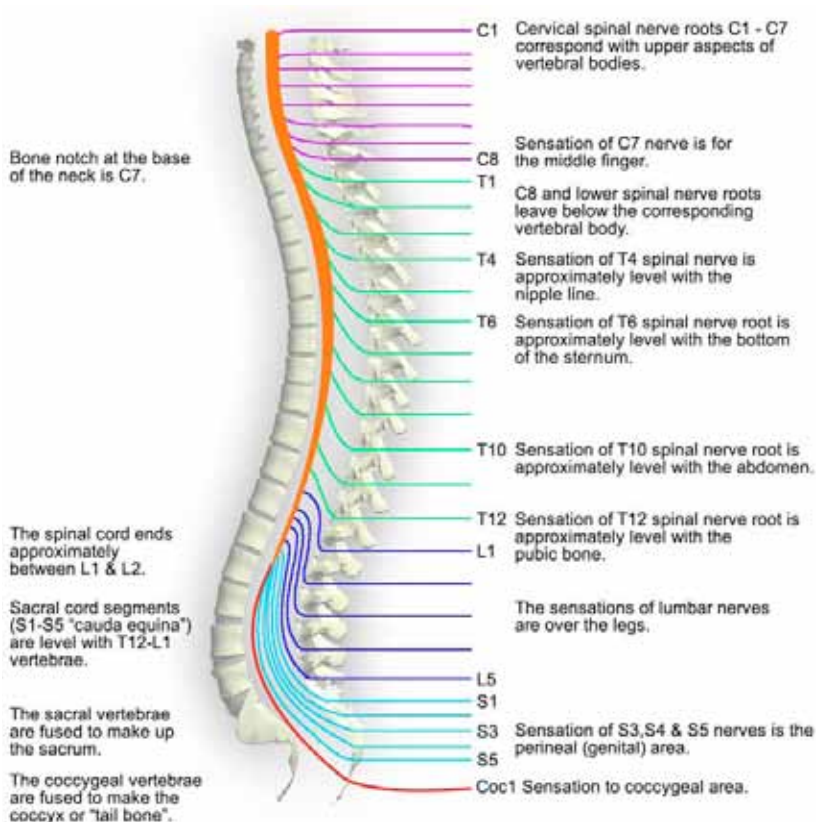
**Lumbar** 5 vertebrae and 5 pairs of nerves that serve the upper and anterior (front) sections of the legs

**Sacral** 5 vertebrae and 5 pairs of nerves that serve the posterior (back) section of the legs, the bowel and the bladder

**Coccygeal** 4 vertebrae and 1 pair of nerves

Each vertebra is separated by disc or cartilage. These discs act as shock absorbers and prevent the vertebrae from grinding together.

The higher the spinal injury the more muscles become paralysed.



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## What is spinal cord injury (SCI)?

This is where the spinal cord is damaged following major trauma to the spinal cord from a variety of causes. In the majority of cases the cord is crushed destroying nerve cells and nerve tracts or pathways at that specific level within the cord.

The level of injury is the exact point in the spinal cord at which damage has occurred. The levels are determined by counting the nerves from the top of the neck downwards, and these nerves are grouped into four different areas, **Cervical**, **Thoracic**, **Lumbar** and **Sacral**.

## Tetraplegia or (and) Quadriplegia

**Tetraplegia:** If your spinal cord has been damaged in your cervical region (neck), all four limbs are affected.

**Paraplegia:** If your spinal cord has been damaged below the level of T1, both your legs are paralysed but this does not affect the hands and arms.

Spinal cord injuries are classified as either **complete** or **incomplete**.

A '**complete**' spinal cord injury means there is complete loss of movement and feeling below the level of the injury. There are no messages getting past the area of damage.

It usually takes a significant trauma to the spinal column, such as a complete dislocation, or 3 column fracture to the vertebra to cause a complete injury. This causes the spinal cord to be crushed and completely compromised.

An '**incomplete**' spinal cord injury means there is either some voluntary contraction of the anal ring, and or some deep anal sensation. This is often accompanied by some voluntary movement and sensation with in the limbs below the spinal cord injury level. Only part of the spinal cord has been damaged and some messages are getting through.

Different types of incomplete injuries

### There are different types of incomplete injuries:

- Central Cord Syndrome
- Anterior Cord Syndrome
- Brown Sequard Syndrome
- Posterior Cord Syndrome
- Conus Medullaris Syndrome
- Cauda Equina Syndrome

### Central Cord Syndrome

As we get older we develop arthritis in our neck with the ligaments, discs and joints of the neck stiffening, and osteophytes (extra bone formations) forming within the spinal canal.

This means there is less space for the spinal cord and increases the risk of significant injury to the cord following relatively

minor injuries. This could be as simple as falling from a standing position and hyper-extending the neck. The spinal cord then becomes stretched over these osteophytes (extra bone formations) causing central bleeding and swelling within the cord.

Someone with central cord syndrome can usually control their legs better than their arms. These individuals sometimes recover enough to walk a little but often continue to have major problems with their arm function.

### **Anterior Cord Syndrome**

Normally this is caused by the fractured vertebra crushing the front of the spinal cord. The nerve pathways at the front of the spinal cord are damaged resulting in these patients being fully paralysed with the loss of hot and cold or pain sensation. The pathways at the back remain undamaged. These pathways transmit sensation from the body to the brain regarding light touch to the skin, vibration sense and the ability to know the position your joints are in without needing to look at them i.e. elbow straight or bent.

### **Brown Sequard Syndrome**

This kind of incomplete injury is caused when one half of the spinal cord is damaged more than the other. It could be caused by one side of the vertebra unilaterally dislocating while the other side stays in place, or it could be due to a stabbing injury where the penetrating object damages one side of the cord.

This results in paralysis of that side of the body, along with a loss of light touch, and joint position sense. However the paralysed leg continues to feel sharp or blunt, hot or cold as these sensations travel to the brain on the opposite side of the cord. The other side of the body remains under voluntary control and can still feel light touch and joint position. It cannot, however, feel hot or cold, or sharp or blunt as these sensations travel to the brain on the opposite side of the spinal cord.



## Posterior Cord Syndrome:

This is a very rare incomplete injury and usually is caused by a medical mishap such as a tumour or lack of blood supply. The only part of the cord to be damaged are the posterior nerve pathways.

There is good voluntary muscle power and they can feel hot or cold, sharp or blunt but they have no light touch, vibration or joint position sense. They therefore find it very difficult to control movement, as they cannot feel the ground beneath their feet or they cannot tell how hard to hold a delicate object etc.

## Conus Medullaris Syndromes

Here a fracture of the T11/T12 vertebra has damaged the spinal cord at the level of the 5th Lumbar nerve. This means that the cord below the injury level still has its spinal reflexes particularly to the bladder and rectum. The legs however remain paralysed as the peripheral nerves from L1 to S2 are damaged and so the muscles receive no nerve impulses from the spinal cord and are therefore flaccid.

## Cauda Equina Syndrome

A substantial fracture or dislocation of the L1 vertebra will damage the peripheral nerves from L1 to S4/5 and so the legs are paralysed. The muscles receive no nerve impulses from the spinal cord and are therefore flaccid. This also means that the bladder and rectum, and or anus also exhibit a flaccid paralysis.

## Further Information

If you have any questions about your spinal cord injury, please speak to the staff.

# Psychological Adjustment after a Spinal Cord Injury

## Introduction

Spinal Cord Injury has far reaching consequences. There are many adjustments to adapt to life after injury, both physically and psychologically.

Following admission to Edenhall, it can be difficult to take in the reality of your situation. There may still be uncertainty regarding your condition and your thinking may be clouded by medication or stress.

Your medical consultant will discuss your case with you and your family. Some people find it is helpful to understand their injury in detail and learn how it will impact on their future. For others, this can seem overwhelming. You can guide the staff as to how much information you and your family want.

## Early Stages

People experience a wide range of emotions after their injury. It is normal for both you and your family to be distressed and upset.

Our initial emotional reaction is often influenced by:

- What we were like before the injury
- Poor Sleep
- Medication
- Head injury (if applicable)
- Alcohol or drug withdrawal (if applicable)
- Being on bed rest (boredom)

With time, people begin to understand their situation and emotions tends to settle. At this point, thoughts often turn towards rehabilitation and regaining independence.

## Rehabilitation

It is likely that you will get used to the staff and procedures in Edenhall during the few weeks that you are there.

Once you are medically well, we will move you to our rehabilitation ward – Philipshill. While this is a positive step, it will be something new and as such, some may find this change stressful. Staff from both wards will meet with you to discuss this transition and answer any questions you may have.

After spending time on bed rest, people tend to look forward to 'getting up'. This often means a slow transition period from being in bed, to brief periods in a wheelchair. People often notice a lift in their spirits at this point as their thinking begins to focus on rehabilitation and increasing independence. For others, it can bring greater insight into the challenges that lie ahead.

During rehabilitation, people tend to focus on making physical improvements. Some may ignore the psychological stresses that they are under. In the short term, this can let people feel a little more in control. However, if you should experience difficulties with anxiety, begin to avoid situations, or develop feelings of depression, guilt, or hopelessness, then there are benefits to discussing these feelings.

## Clinical Psychologists

Clinical Psychologists tend to see people who are finding life more challenging than normal. The psychologist will meet you for a brief interview while you are on the Edenhall ward. This is mainly to find out how you are coping and if you have any concerns.

As your rehabilitation progresses, many people find it is helpful to reflect on their emotions. While some people may have mild changes in their emotions, others can experience more significant difficulties. The type and frequency of psychology input will vary according to what you see as being helpful.

**Please note: all discussions with the clinical psychologist are confidential.**

## Long Term Outcome

How someone copes in the longer term does not depend on their injury. Some people assume that a more debilitating injury

is somehow worse. Research suggests that this is not the case. The most influential factors tend to be:

- How someone perceives their situation
- Belief that they can cope and influence their situation
- Social Support
- Meaningful activity (e.g. hobbies)

People continue to adapt to their new situation over the course of their rehabilitation and in the years that follow.

Some will adjust with ease while for others, it may be tougher and they may benefit from additional support. You can access ongoing psychological support via your GP after you have been discharged.

## Relatives

While spinal injury impacts you, your relatives tend to experience a very similar emotional reaction. They will have many of the same worries and fears that you have. Discussing these worries with each other can be reassuring and help you feel more secure.

The clinical psychologist also provides emotional support and information to your relatives. They can make appointments for one-to-one sessions or family meetings.

The psychologist also runs monthly meetings to introduce new families to the unit and explain the rehabilitation process.

## Contact Details

If you or your relatives would like to discuss anything with the clinical psychologist, please contact.

### **Dr Campbell Culley, Clinical Psychologist**

 Telephone: **0141 201 2547**

 E-mail: **[campbellculley@nhs.net](mailto:campbellculley@nhs.net)**

The clinical psychology office is opposite the hydrotherapy pool. Please knock on the door if you have any concerns at any stage in your rehabilitation.

## Personal Stories

### Written by the Husband of a Tetraplegic Lady (2012)

*My wife had an accident 12 years ago which left her fully dependent as she had a complete C5/6 injury. My first reaction was sheer panic and every time I visited my wife it broke my heart to see her lying in a hospital bed. Before her accident she was always on the go and had a well paid job that she loved.*

*We have three boys and one of them, aged 16 at the time, took a very long time to accept the change that the accident had made to his mum; seeing her in a wheelchair. The medical staff in the Spinal Unit could not have been more helpful; they were honest with us and kept us informed at all times also encouraging family and friends to assist with my wife's care where appropriate. We began to become more confident in my wife's care and needs during her time in hospital. I found it really difficult to face my wife every day especially when she was at her lowest and I knew there was nothing I could say or do to help her. She worked through her rehabilitation and as she progressed daily her spirit lifted a little at a time.*

*It was not until my wife left hospital that some normality started to return to our lives. Our house had to be adapted and through Motability we leased a wheelchair accessible van. At this point it was essential to find out what benefits my wife would be entitled to help her with her daily life. She now employs her own Personal Assistant's (PA) to help her live her life more independently.*

*Looking back I cannot believe what she and indeed our family have achieved since her accident. We now have three grandchildren and two small dogs which keep my wife, her PA's, and myself very busy. She is always out and about and at times I cannot find her! We have even been on holiday, several times now abroad, something I thought we would never do.*

*I am not saying that life is easy and obviously there will be times when things seem worse than others, but there is life after the Spinal Unit and we will just take each day as it comes. I am a very private person and find it difficult to put into words how I felt at the time; I am writing this in the hope that our experience may help others.*

## Day to Day Routine with a Spinal Cord Injury

*Planning ahead makes a huge difference when living with a spinal injury as it will make your day much easier.*

*Simple tasks like leaving out clothes the night before can save time in the morning. Leave clothes out within reach of where you are going to be changing and make sure that you have left everything that you require, including footwear.*

*If you are going to travel by public transport it might be necessary to give notice to the provider beforehand and give as much notice as possible of your arrangements.*

*If you plan on going out for a day, make sure that you have enough medication with you, if you take any, and make sure there is facilities that will allow you to deal with toileting. If you use intermittent catheters, it will not do any harm to add another few in a bag just in case you get stuck somewhere.*

*If you are travelling by car either on your own or with someone it would be useful to have a way of dealing with bladder issues such as spare catheters, leg bags and even overnight bags, as you never know if you are going to be stuck in the car due to unforeseen circumstances such as floods or snow and you are not able to return home. At least if you have some way of emptying your bladder you are limiting the risks and there should hopefully not be any accidents.*

### Spasms

*I had problems with spasms in the early days of my injury but now they are well controlled on medication. My spasms do however get worse if I have a problem such as a Urinary Tract Infection (UTI) so they are helpful in letting me know that something is wrong.*

### Bowels

*It took me a long time to get a bowel routine established while I was in hospital. It was one of the most difficult things about my rehab but once established I have had very few problems since.*

### Bladder

*While in hospital and for a year after, I used intermittent catheterization. It was difficult to begin with to manage to catheterize from my chair but with practice I managed. After a year and in discussion with medical staff I opted for a suprapubic catheter which I find much easier to manage.*

### Skin

*I have been very lucky and have had no skin problems either in hospital or since discharge but I am aware of the problems that may occur and take care of my skin in order to avoid them.*



### Neurogenic Pain

*Having neurogenic pain has been the hardest thing for me to deal with in the long term. My pain did not start until about three months after my injury but then continued to get worse leading to increased medication to try to control it. Some days are better than others for no reason. It does not seem to follow any particular pattern. I find distraction is the best therapy and in particular exercise. The good news is that there is a lot of research being done in various different centres so hopefully there will eventually be a way of controlling the pain.*

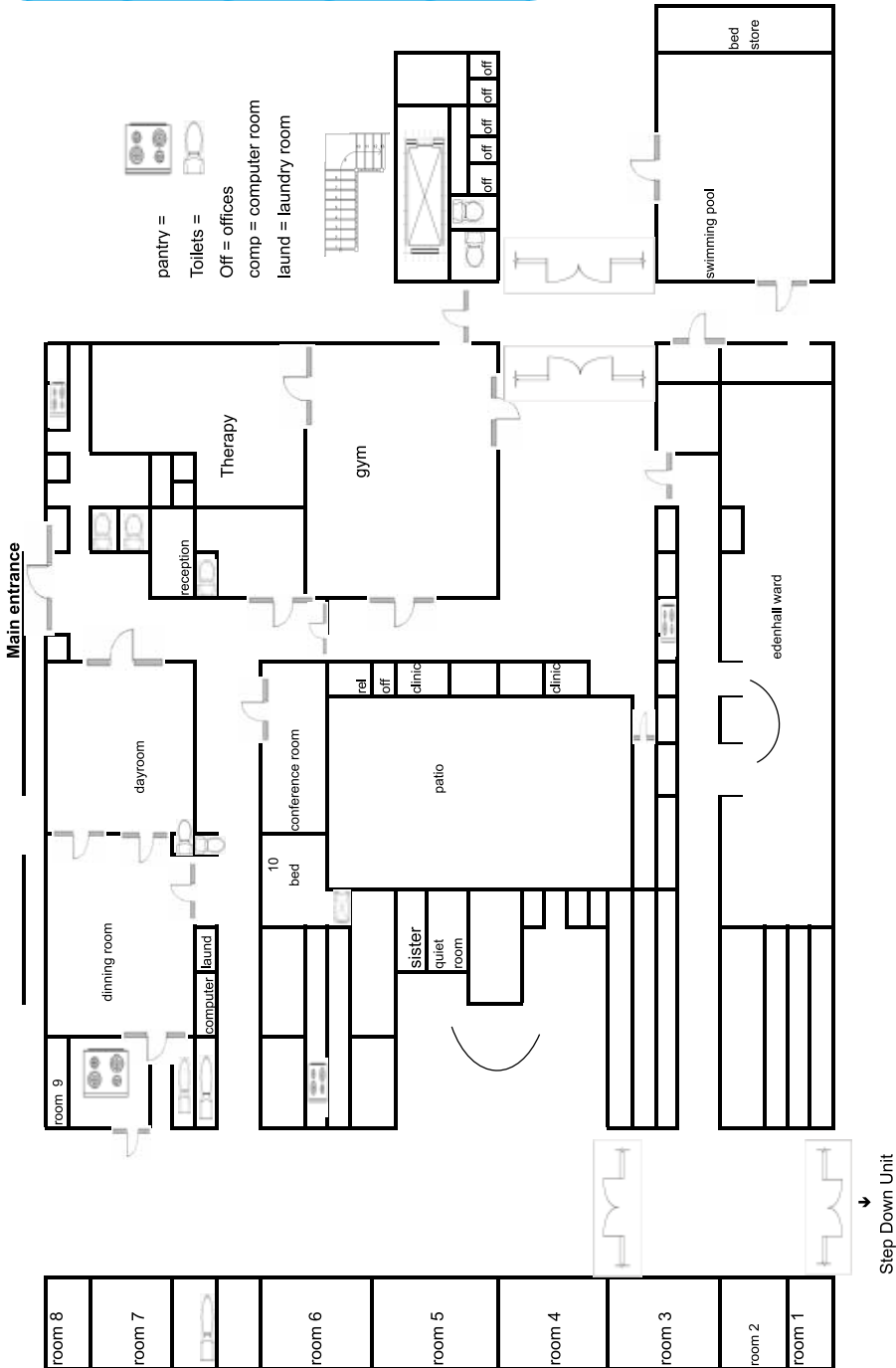
### Staying Fit And Well

*I have a hand bike and it is by far the best purchase I have made since having my spinal injury. I used to run prior to my injury. I still go out with the friends that I ran with previously only now on my handbike. I also go to races with them. I try to get out at least three times a week it makes such a difference to how I feel, just getting out in the fresh air and exercising.*

### Holidays

*I was a bit nervous of flying for the first time so I did it with some friends along for support. Since then I have taken numerous flights on my own and always found the staff at the airports to be more than helpful.*

# Spinal Injuries Unit Floor Plan





## Section 2

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## Respiratory Complications after

## Spinal Cord Injury

### The Respiratory System

When you breathe in, air is drawn in through your mouth and nose and is then carried into your lungs via the trachea (windpipe) which then splits into 2 branches called the bronchi, one for each lung. The bronchi continue to split into many smaller branches called bronchioles and the air eventually ends up in air sacs at the end called alveoli. Oxygen is then passed from the alveoli into your blood stream and carbon dioxide is passed back the way through your lungs and is what you breathe out through your mouth and nose.

Healthy lungs produce a small amount of mucus (phlegm) each day which we clear without even thinking about it. The main role of this mucus is to protect your lungs by trapping any dirt, debris or bugs.

Respiratory muscles bring about movements in your chest to allow you to breathe and clear your lungs and can be affected by spinal cord injury just like the muscles in your arms and legs (see Figure 2). These muscles can affect how big a breath you take in, or breathe out and also give you force behind a cough or a sneeze (see Table 1 for details on these muscles).

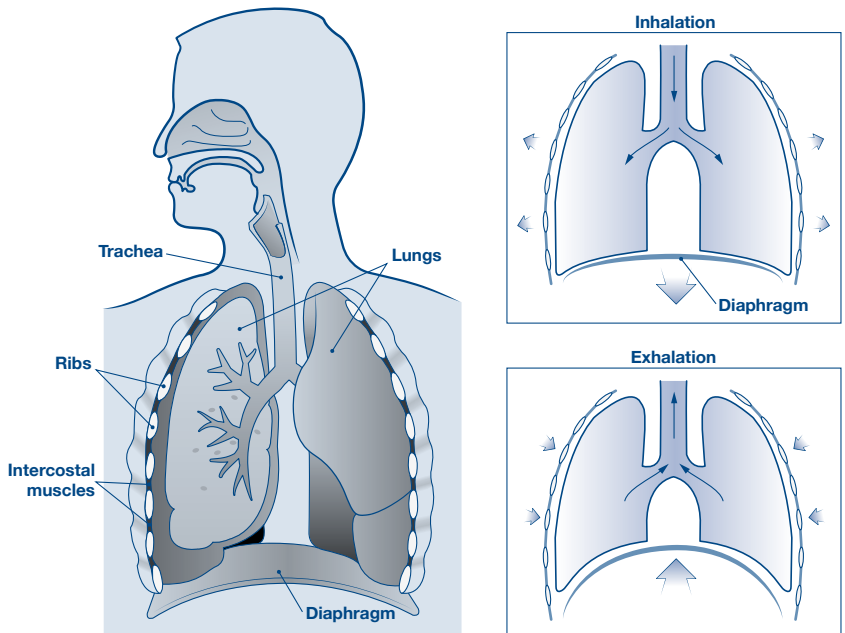
**Table 1 - Muscles of the respiratory system.**

<b>Muscle</b>	<b>Spinal Nerve</b>	<b>Normal Function</b>	<b>After Spinal Cord Injury</b>
Diaphragm	C3-C5	Contracts downwards to lengthen your thorax which pulls air down in to the lungs	If your diaphragm doesn't work well enough, you will need a ventilator to breath
External Intercostals	T1-T10	Lifts your rib cage up and out to make your breath deeper	Rib cage won't move as much when breathing in, resulting in smaller breaths. This may make you more tired or make it difficult to clear mucus.
Scalenes Sternocleidomastoid (Accessory Muscles)	C4-6 C2-3	Only used when breathing is stressed e.g. during hard exercise	Can assist breathing if your diaphragm is weak
Abdominals	T6-12	Contract powerfully during a cough to help push out anything in your lungs. Also maintains abdominal pressure making it easier for your diaphragm to function	Weak cough. Diaphragm has to work harder as it sits in a poorer position due to lack of abdominal pressure.
Internal Intercostals	T1-T10	Push your rib cage down and in to compress your lungs and push anything out.	Weak cough.

## Am I likely to have problems with my respiratory system after SCI?

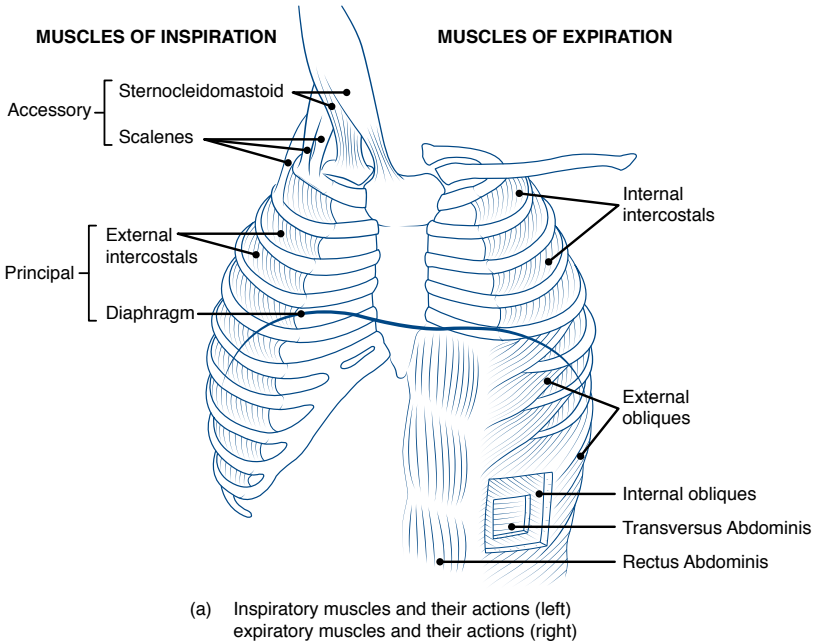
Generally speaking, the higher the level of your injury, the more severely it will affect your respiratory function.

- People with tetraplegia will be most affected (C1-C8) with some needing lifelong assistance with breathing.
- Low level injuries (below T12) are unlikely to be affected as there is no direct respiratory muscle paralysis but it is still important to keep active to maintain a healthy respiratory system.
- Motor complete injuries will be affected more severely than motor incomplete injuries.



**Figure 1 – Respiratory system and function of diaphragm when breathing**

## Figure 2 – Different muscles involved in breathing.



### What happens immediately after SCI?

Some people need ventilation at the time of their injury but this may be due to a number of other factors such as reduced consciousness, chest trauma or other injuries. Ventilation involves a machine giving you support to breath through a tube. We may insert the tube into your mouth or nose before passing down your trachea to your lungs. This tube may be changed to a tracheostomy tube (see information on Tracheostomies below) which is a tube that goes directly through your neck via a surgical cut to your windpipe.

Once the doctors feel you are well enough, they will gradually reduce the amount of support the ventilator is giving you and allow you to build up strength in your respiratory muscles. If this is successful, you will spend increasing periods off the ventilator before we remove the tube. This process can last from days to months.

In other cases, people are breathing well initially after injury but after a few days their respiratory muscles tire as they are not

functioning normally. They may need a period of ventilation to allow them to rest and build up their strength again.

## **Tracheostomies**

Tracheostomies are for people that are likely to be on a ventilator for more than a couple of weeks. This is because it is more comfortable for the patient and may make it easier to gradually reduce the use of the ventilator. If you are well enough, the nurses can place a speaking valve over the tracheostomy to allow you to speak and you may be able to eat and drink. Speech and language therapists will assess and monitor the strength of your swallow to determine what is safe for you to eat and drink. If you eat and drink when your body is not ready, it may go down the wrong way into your lungs rather than your stomach and cause infection.

## **What happens if I can't get off of the ventilator?**

Unfortunately for some people, they may always need 24 hour support from a ventilator as the diaphragm is not strong enough to keep you breathing. If this is the case, we will gradually reduce the use of the ventilator to a small portable one that works from a battery and allows you to get out and about.

Some people may only need overnight ventilation. In this case, you have enough strength to breath during the day but your muscles can't manage overnight when the muscle tone in your respiratory system relaxes. Having a period of overnight ventilation can give you more energy during the day and, in some cases, this may be via a face mask rather than an invasive tube.

## **Why is it harder to cough and clear mucus after SCI?**

This can happen for a number of reasons, the main reason being weakness in the abdominal and internal intercostal muscles. Also, if you are unable to take a deep breath in, it is difficult to get air behind the mucus to cough it up. If you are unable to clear your own mucus, you may need an assisted



cough. This is where someone places their hands over your tummy and pushes up and under your diaphragm as you cough to replicate the force that is normally created by your abdominals. It is also possible to assist yourself with a cough if you can pull your forearm in against your tummy.

If you can't clear your chest with an assisted cough alone, you may need respiratory physiotherapy where varying pressures, springs or shakings are performed over the rib cage by someone to loosen your mucus. A cough assist or suction machine may also be necessary to help clear your chest.

### **What can I do to help my respiratory function?**

If you smoke, give up! Smoking is harmful to your chest and will make your breathing more difficult and mucus harder to clear.

Regular exercise will help maintain a healthy respiratory system. We also advise you to get the flu jab at your GPs surgery each year.

If you suspect you may have a chest infection or notice any change in your breathing contact your GP as soon as possible.

If we know you have problems with your respiratory system after SCI, we will have a management programme in place to help keep your lungs healthy. Please follow the advice the respiratory care team or your physiotherapist gives you. If you are on medications for your chest (inhalers or nebulisers), take them as prescribed as they open up the airways in your chest and help you clear mucus. If you use a cough assist machine, use it every day or if you need chest physiotherapy, do this every day, this will stop mucus building up and your rib cage from getting stiff.

## What are the signs of a chest infection?

If you have a chest infection you may feel short of breath, tightness in your chest and have a raised temperature or cough. The mucus in your chest will become thicker and your lungs will produce more mucus to help clear your lungs of infection. You may also notice that mucus becomes yellow, green or brown. Healthy mucus is clear or white. If you think you have a chest infection, change position regularly to help move the mucus out of your chest and drink plenty fluids as the mucus will be harder to clear if you are dehydrated.

- If you have any questions about your chest, speak to your consultant, the respiratory care specialist nurse or your physiotherapist.

## Skin Care after your Spinal Cord Injury

### Pressure Area Care

Pressure area care means looking after your skin to prevent it from breaking down (also known as pressure ulcer or pressure sore).

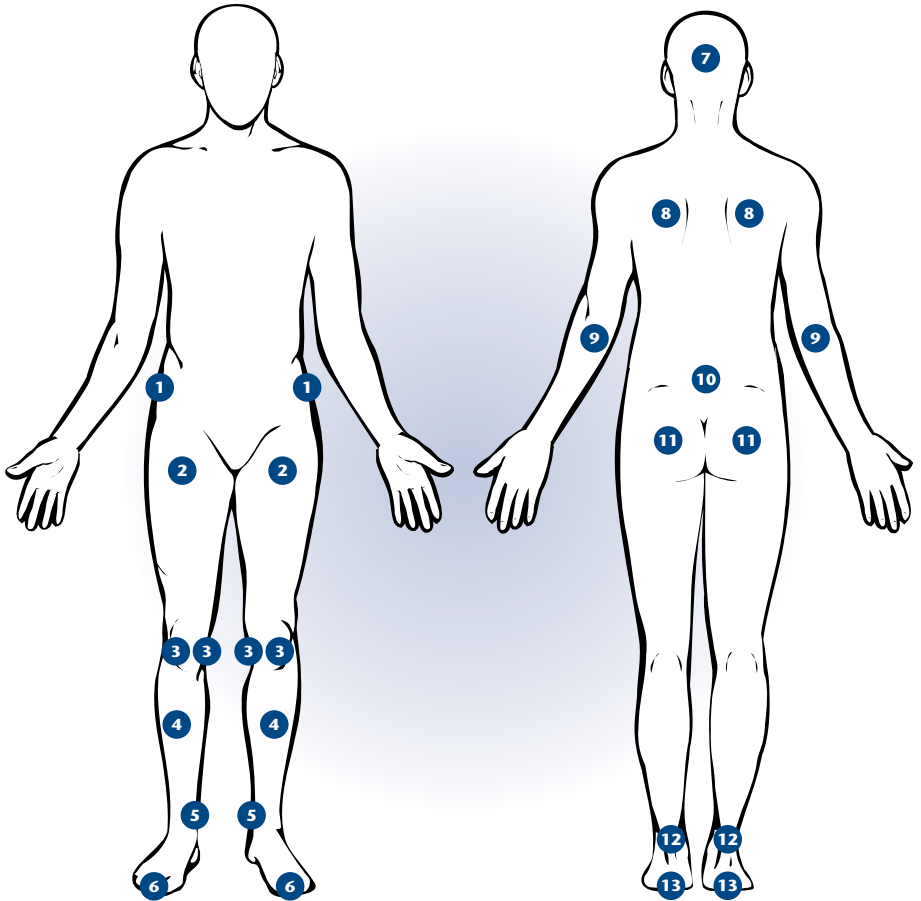
### What is a pressure sore?

A pressure sore is an area of damaged skin and flesh. It usually starts with the skin changing colour e.g. redder or darker than usual. If left untreated a blister or open wound can develop. Over a period of time this will result in a deep hole in the skin and underlying tissues.

It is better to prevent them as they can take a long time to heal. If they are left untreated complications may occur which could be fatal.

### What areas are at risk?

Everywhere is at risk but particularly skin areas over bony prominences, e.g. hips, knees, elbows, lower back, buttocks etc. (See diagram on next page).



1. Hips
2. Trochanters
3. Front and inner sides of knees
4. Shins
5. Ankles
6. Toes
7. Back of head
8. Shoulder blades
9. Elbows
10. Sacrum
11. Buttocks
12. Ankles
13. Heels

## What causes pressure sores and how can I prevent them?

Below is a list of things that can cause pressure sores:

### Pressure

Pressure on the skin means blood cannot get to it. When you take away the pressure the skin becomes pink from the blood supply returning to the tissues. Usually skin colour returns to normal after 15-20 minutes. If skin colour does not return to normal after this time damage has been done to the underlying tissues.

If possible try to take the weight off any vulnerable area every 15 minutes or so by changing position e.g. turning onto other side when in bed, lifting up when sitting in a chair.

### Shearing

This is the sliding of skin over bone e.g. sliding down the bed, dragging your bottom against the wheel when transferring. Think about your transfer technique and discuss with your physiotherapist any alternatives or aids to assist if needed.

### Friction

This is rubbing of one surface against another e.g. ankles or knees rubbing together.

Consider using pillows when in bed to separate your legs and prevent them rubbing together.

### Excess Moisture

The most likely causes are sweat, urine or faeces. All of these are waste products which have harmful toxins that work like acids when in contact with the skin.

Wash your skin thoroughly and keep it dry. Avoid using talcum powder which clogs up the skin.

## **Anaemia**

This means there are fewer red blood cells to carry oxygen to the tissues. Eat a healthy diet rich in iron (e.g. spinach, broccoli, breakfast cereals or nuts). Your doctor may prescribe iron tablets depending how severe the anaemia is.

## **Underweight or overweight**

Underweight people have less padding around the bony parts and overweight people have excess pressure around the bony parts. Eat a healthy diet and drink plenty of water. We recommend you drink 2 litres each day unless your doctor tells you otherwise.

## **Steroids**

Long term use of steroid makes the skin thin.

## **Infection**

Infection often causes an increase in temperature and sweating therefore, increasing moisture. Check your skin more often when you have an infection. You may need to increase how often you turn or reduce the time sitting in your chair if you have an infection.

## **Nutrition**

Your diet can affect the healing process. Protein promotes wound healing (e.g. red meat, milk, eggs.) Vitamin C (e.g. oranges, tomatoes) promotes skin's elasticity or suppleness. Make sure you include these in your diet.

## **Smoking**

Smoking narrows blood vessels, which reduces the circulation to the skin making the skin more at risk. There is also the risk of burns from hot ash (see section on heat or cold).

## Wheelchair, cushions, shower chair or commode

Your wheelchair cushion gives you postural support and weight distribution and therefore skin protection. However, sitting the wrong way can cause pressure sores. The areas at risk are sitting bones, base of spine, the back of heels and palms of hands.

To reduce the risk of skin breakdown:

- Relieve pressure at least once every 15 minutes.
- Avoid, knocking toes, feet and ankles during transfer.
- Use an appropriate cushion.
- Make sure the cushion is placed the right way round.
- Make sure the Roho cushion, if used, is set at the right pressure.
- Make sure your wheelchair is set up correctly.
- Make sure all bolts and screw heads are covered.
- Contact your local appliance department if you develop problems with your wheelchair or cushion.
- Use padded shower chairs.

## Heat or Cold

Your spinal cord injury can affect your awareness of temperature sensation. This means that you are more at risk to heat and cold damage below your level of injury. Often the paralysed body takes on the environmental temperature (called poikilothermia) due to an inability to shiver or sweat normally.

To reduce the risk of skin breakdown:

Check water temperature.

- Do not rest hot drinks or food on your chest or knees.
- If hot drinks are spilt on you, check the area for scalding.
- Do not use a hot water bottle or electric blanket.
- Keep a safe distance from fires, radiators and hot water pipes.
- Dress appropriately for the temperature of your environment.

- In warm weather use a high factor sun cream and do not stay out in the sun too long.
- If you are lying on a sun lounger place your wheelchair in the shade as the metal frame can get very hot.
- Try to give up smoking to reduce the risk of you burning yourself with ash.

## Clothing

Many items of clothing and accessories can increase pressure on your skin.

To reduce the risk of skin breakdown:

- Trousers and Denims
  - » Should be looser at the waist, hip and crotch areas
  - » Avoid thick seams, buttons, pockets, remove studs
  - » Avoid putting keys or loose change in pockets or holding them between your legs
- Skirts
  - » Should be looser at the waist
  - » Avoid skirts with buttons or zips at the back
- Shoes
  - » Should be one size larger than normal to allow for swelling
  - » Should not be tied too tightly
  - » Check feet extra carefully when wearing new shoes
- Underwear
  - » Ideally do not wear underpants
  - » If worn should be seamless and well fitted
  - » Avoid nylon underwear as it increases sweating
- Socks
  - » If seams are thick wear inside out



- Accessories
  - » Be careful with belts and buckles
  - » Make sure anyone washing or turning you does not wear jewellery, watches, rings and bracelets as they can scratch your skin

Overall you have to actively look after your skin. You have to prevent and predict skin damage before it occurs.

Always check your skin when you change position or change from one surface to another. Use a long handled mirror for areas you cannot see. If you cannot check your own skin make sure whoever is assisting you checks it and tells you what they see. Increased spasm or excessive sweating may be a sign of damaged skin. Good posture is important. Slouching can lead to skin over the tail bone breaking down.

If your skin is damaged e.g. redness, swelling, bruising, blistering or broken, it's important that you relieve pressure to the area. This may mean staying in bed to allow complete pressure relief. **Pressure sores can take a short time to form and a long time to heal.** The good news is you can prevent pressure sores if you find them quickly and take immediate action. **Unfortunately if you ignore them, then they can be life threatening.**

## Skin Tolerance

Skin tolerance is the length of time a person can lie or sit on one area without getting a red mark. Everyone's skin tolerance is different.

It is important to know what your skin tolerance is. If lying or sitting on a different surface than usual your skin tolerance time may be different so if you are trying a new surface for the first time, check your skin on a regular basis.

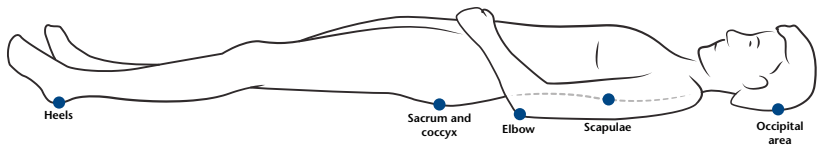
## How often should the skin be checked?

Whilst in hospital we will check your skin, or encourage you to check your own skin every time you get up or return to bed. This is to establish what your skin tolerance is. By the time you go home you should know what your skin tolerance is. Routinely you should check your skin twice a day. Once before getting up in the morning and going to bed at night. However, if you have any skin problems you need to check your skin more often.

## How to position yourself in bed

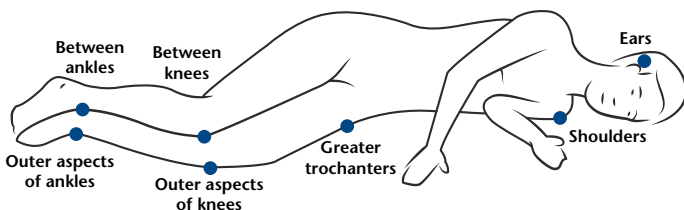
If your skin tolerance is 8 hours that means you should turn every 8 hours. If it is 6 hours then you should turn every 6 hours etc.

**When lying on your back the risk areas are:**



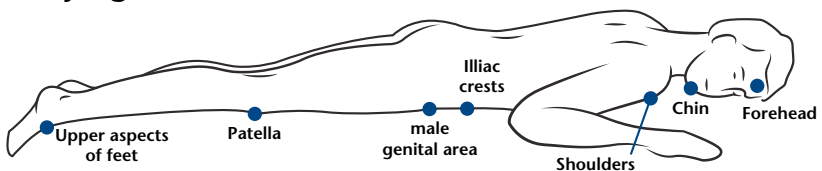
Placing pillows under risk areas can help in relieving pressure.

**When lying on your side the risk areas are:**



Placing pillows at risk areas can help in relieving pressure.

**When lying face down the risk areas are:**



Using pillows at risk areas can help in relieving pressure. Lying face down is also good for straightening your hips and knees and can reduce leg spasms.

## Pressure relieving in your wheelchair

When sitting in your chair, it is important that you pressure relieve regularly. You can do this in a number of ways.

### Lifting buttocks from chair

In order to do this you need to have good arm strength. Apply brakes and push up either from the armrests or wheels until your buttocks are free of the chair.

Count to 20 slowly and then come back down again.

Do this every 15 minutes.





### **Leaning from side to side**

If you do not have good arm strength then going from side to side is an alternative. Apply brakes, hook your arm around back of chair and then lean to opposite side that takes the pressure off that side of the buttock.

Count to 20 slowly and repeat on the other side.

## Tilting forward

This is another effective method but again you need good arm and balance control unless there is someone to help you. Apply brakes; bend forward moving your chest towards your knees, balancing by leaning your arms on your upper thighs or wheelchair. This lifts the weight of the buttocks off the chair seat.



## Bed Rest

If a red mark develops over your hips, buttocks, or lower back, stay off the area. This means staying in bed.

Do not overcompensate by overworking one side to relieve the other or you will end up with marks on both sides.

Once the mark has faded then increase the time lying on that side gradually i.e. by 30 minutes. Do not continue to increase time if skin gets marked.

For pressure relieving purposes, place pillows over the bony prominences i.e. under ankles, between legs. Do not place legs directly on top of one another. Take care when placing pillows between thighs to avoid pressure or sweating on the groin and genitalia and also at the back to avoid pressure or sweating on the sacrum or buttocks. When using a pressure relieving mattress e.g. air mattress, you do not need pillows underneath your ankles.

## What do I do when skin has healed?

If there has been a skin problem requiring a period of rest in bed then once it has completely healed, gradually get up.

If in any doubt please contact a member of your Spinal Unit Team.

### Always Remember

1. Check your body every morning and every night! Use a mirror for areas that can't be seen.
2. Take action immediately! The moment you detect a red mark or even suspect a pressure area is forming you must go on bed rest and remain there until your skin is completely healed.
3. Always get advice from the liaison team or your district nurse.

### Skin

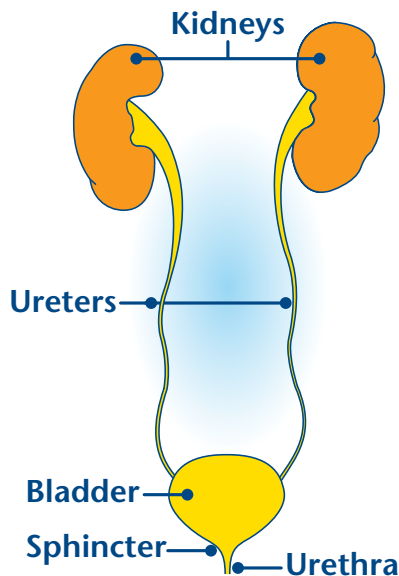
*I have been very lucky and have had no skin problems either in hospital or since discharge but I am aware of the problems that may occur and take care of my skin in order to avoid them.*

## Managing your bladder

When you have a spinal cord injury it can cause changes in the way your bladder works. Paralysis at any level will almost always affect bladder function; therefore normal control of passing urine will be lost.

Taking care of the bladder is very important to anyone who has a spinal cord injury therefore correct management is essential.

To understand the importance of good bladder management it is useful to understand the urinary system.



### Kidneys

These remove waste substances from the bloodstream to form urine.

### Ureters

These are two thin tubes which drain the urine from the kidneys to the bladder.

### Bladder

This stores urine until it is convenient to empty.

## **Urethra**

This is where the urine is released.

## **Sphincters**

These are muscles at the base of the bladder, which act like automatic doors that open at the right moment to allow urination.

## **How has my bladder been damaged?**

Following an injury to the spinal cord, the nerve control from the brain to the bladder no longer works. The brain doesn't know when the bladder is full and therefore cannot control emptying the bladder.

## **Different types of Bladder**

How the bladder functions depends where the spinal cord is damaged.

### **Reflex Bladder**

This occurs if you have an injury at T12 or above. The nerves that cause your bladder to empty are still working. When the bladder is full a reflex will automatically trigger it to empty, although you may have no control over this.

### **Flaccid Bladder**

This occurs if you have an injury below T12. The reflexes are absent or weak, therefore the bladder will continue to fill, when the bladder overfills, dribbling occurs.



## Mixed Bladder

This can occur when there has been only partial damage to the spinal nerves. Results can be very mixed. You may have the feeling you need to go the toilet but have no control over it, or you may have no feeling but may be able to pass urine. Management will depend on your symptoms.

## Methods Used for Managing your Bladder

The methods to manage your bladder will depend on:

- Your type of injury
- What is suitable for you

Your nurses, doctors and key workers will help you through this process, by offering advice, guidance and support both as an inpatient and outpatient.

Bladder training is a process to teach you how to manage and empty your bladder. The type of bladder training depends on your bladder behaviour.

## Catheters

As part of your bladder management you may have a catheter. There are different types of catheters.

After your injury we insert an indwelling catheter as this gives health care staff information about your kidney function.

## Indwelling Catheter

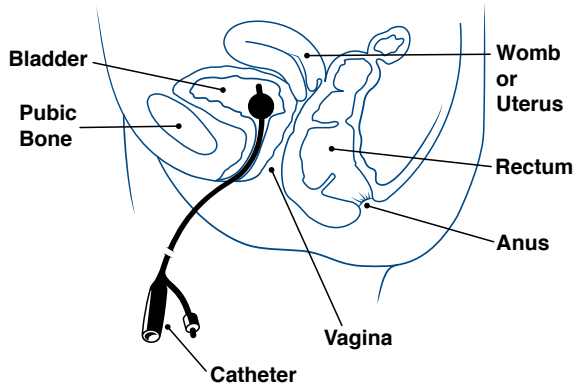
This catheter is inserted into the bladder through the urethra. Once inserted, a small balloon is inflated with water to keep it in place. A catheter bag is attached to the catheter which can be worn on the thigh or calf.

We recommend an indwelling catheter is changed every 6 weeks to reduce the build up of sediment (dregs) and prevent blockages.

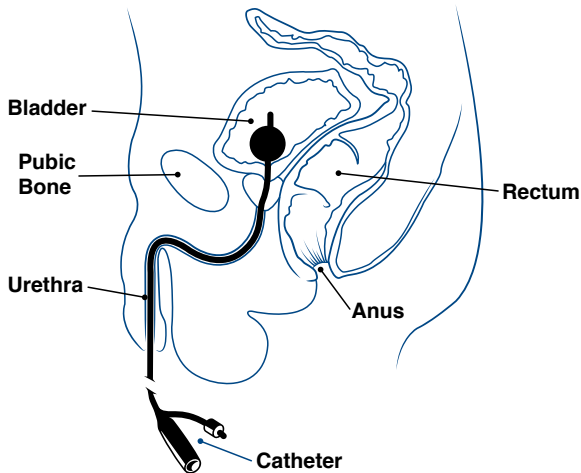
Staff will show you how to insert an indwelling catheter so that you can do this yourself or tell your carer how to do this.

## Indwelling catheter diagrams

Female Urinary Tract with Catheter in place



Male Urinary Tract with Catheter in place



### Supra-Pubic Catheter

The doctor will make a small cut above the pubic bone and then insert the catheter directly into the bladder through the abdominal wall. A drainage bag will be attached to the catheter which is then attached to the thigh or calf.

We recommend this catheter is changed every 6 weeks. At first the doctor will change the catheter, then after this a nurse will then change your catheter. We may teach you or your carer how to change the catheter.

## **Intermittent Catheterisation (ISC)**

Intermittent catheterisation allows you to empty your bladder regularly without having to wear any appliances such as a catheter bag.

You insert a catheter directly into the bladder through the urethra every 4 hours. You empty the bladder then remove the catheter.

Before you start using intermittent catheterisation, your nurse will discuss this with you and will teach you how to do this. Please note, it can take several days for you to learn how to do this. There is equipment available which can make it easier for you to insert the catheter e.g. adjustable mirrors, velcro fasteners.

When using intermittent catheterisation we recommend that you drink 2 litres of fluid each day.

## **Sheath Drainage**

Men with a reflex bladder may use this form of bladder management. This is a self adhesive sheath or condom which will be measured for you. This is applied to the penis and attached to a leg bag which is then attached to your calf or thigh.

You should replace the sheath every day to prevent infection, and can be used with intermittent catheters.

## Problems that can arise with catheters

Common Problems	Signs and Symptoms	Treatment
<p><b>Urinary Tract Infection</b> (This is when there is a build up of bacteria which will divide rapidly and attack the lining of the bladder and cause infection)</p>	<p>Cloudy Urine</p> <p>Increase in sediment</p> <p>Strong odour from urine</p> <p>Raised temperature</p> <p>Flu like symptoms</p> <p>Increase spasms</p> <p>Incontinence or leakage</p> <p>Dysreflexia (raised blood pressure and slow heart beat)</p>	<p>Drink plenty of fluids</p> <p>Take a urine sample to your GP</p> <p>Contact your GP as you may need an antibiotic</p> <p>Maintain good personal hygiene e.g. always wash your hands before and after catheterisation.</p> <p>You may need to stop using intermittent catheterisation and use an indwelling catheter for a short time.</p>

Common Problems	Signs and Symptoms	Treatment
<p><b>Blocked Catheter</b> (this is when the catheter is blocked, either with sediment or calculi, therefore urine cannot be passed)</p>	<p>No urine, or old cold urine in catheter bag.</p> <p>Distended (swollen) abdomen</p> <p>Increase spasms</p> <p>By-passing or leakage of urine</p> <p>Dysreflexia</p>	<p>If in doubt remove the catheter and re-catheterise, making sure drainage is present.</p> <p>Find out how the catheter is blocking.</p> <p>Increase your fluid intake, contact your GP or Spinal Unit for advice.</p>

Common Problems	Signs and Symptoms	Treatment
<p>Bladder or Kidney Stones (these are tiny granules that can grow in size, you are more prone to these after your injury because you are less mobile and due to loss of calcium from your bones).</p>	<p>Difficulty passing urine</p> <p>Frequently blocked catheters</p> <p>Blood in your urine</p> <p>Frequent urinary tract infections</p> <p>Increase spasm</p> <p>Autonomic Dysreflexia (usually intermittently)</p>	<p>Always make sure the catheter is draining, regularly check your leg bag</p> <p>Increase your fluid intake</p> <p>Reduce foods high in calcium e.g. cheese, milk</p> <p>Keeping the urine slightly acidic will allow the chemicals to remain dispersed in the urine and not form stones. Cranberry juice (if you are not on warfarin), Vitamin C, and citrus fruits can help.</p> <p>Every year have a Kidney Ureters Bladder x-Ray and Renal Ultrasound to check for kidney or bladder calculi. (stones from sediment).</p>

## Supplies and Contacts

When you are in hospital nurses will try different catheters according to your needs and to help you choose.

Before you go home, the staff will discuss what supplies you will need. They will liaise with the continence suppliers, and discuss the most suitable way for you to get these supplies. All this information will be on your discharge letter, which we will send to your GP and district nurse.

If there are any problems with supplies when you go home please contact your district nurse for support and advice.

Our Liaison service will also offer you support and advice and liaise with your district nurses.

# Managing your Bowels

Below is a diagram of the different parts of the digestive system and what they do.

## The Digestive System:

### 1. Mouth

When food is chewed, saliva starts digesting carbohydrates.

### 2. Oesophagus

Muscles, in a process called peristalsis, push the food down into your stomach

### 3. Stomach

Everything is blended with digestive juices. Hydrochloric acid kills bacteria. Enzymes break down proteins.

### 4. Liver

A green liquid called bile which is stored in your liver, is secreted to break down fats.

### 5. Pancreas

Many kinds of digestive enzymes are made here.

### 6. Small Intestine

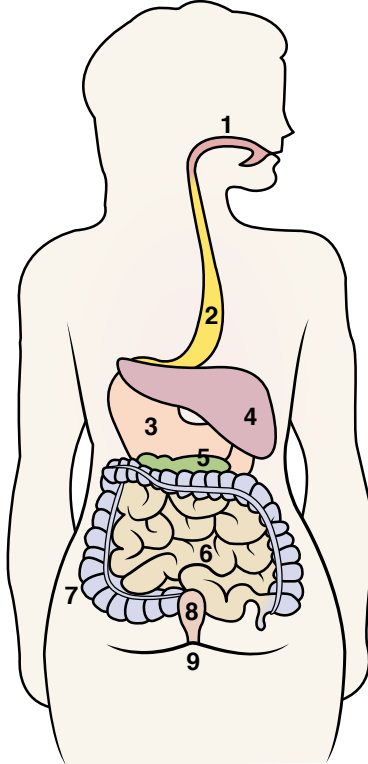
Food is mixed with bile from your liver and juices from your pancreas to be sent back to your liver for more processing.

### 7. Large Intestine

Indigestible food and water are processed, stored and dispersed.

### 8. Anus

Solid waste passes from the rectum in order to leave your body.



**9. Sphincter Muscle**  
The external sphincter is a muscle near the anus that helps maintain continence



## How the bowel worked before your Spinal Cord Injury (SCI)

The bowel is part of your digestive system, whose role is to break down what you eat and drink. After a meal is digested, peristalsis (an involuntary muscle movement) pushes chewed food through the digestive tract.

Peristalsis takes place several times each day, most frequently after meals (the gastrocolic reflex). This movement takes place without any input from the brain or spinal cord and is not affected by your spinal injury.

As the bowel fills with stool it stretches, triggering messages to bowel muscles to move the stool down to the end of the large bowel, and the rectum. Another message coming up to the brain lets it know when it's time to go to the bathroom, to open the anus, and pass a motion. When it's socially convenient we will control our abdominal and pelvic muscles to allow us to empty the rectum to pass a motion. This is often called a bowel movement.

### The science bit!

The bowel is controlled mainly by nerves leaving the spinal cord at level of T6-T12 (lower thoracic vertebrae). These nerves control the movement of abdominal muscles.

The lower end of the bowel is controlled by nerves leaving the spinal cord lower down at level S3-S5 (sacral vertebrae). Some automatic (autonomic) control occurs within the bowel itself; this is the part that brings the urge to use the toilet when stressed or frightened.

### How the bowel works after SCI?

After a spinal cord injury, the messages sent by the nerves located in your bowel are not able to reach your brain as before. This means you will not get the message that tells you when your bowel is full.

You may also lose control of the muscle at the opening from your back passage (sphincter).

Your degree of loss will depend upon your level of injury and the extent (completeness) of your spinal damage.

### Upper Motor Neuron or reflex bowel

If your spinal cord injury is above T12, your bowel will continue to empty when stimulated - either chemical (suppositories) or mechanical (digital stimulation). This is explained later. However, you will lose the control you normally had from your brain. With this type of injury, the message telling you that the bowel is full is not received and the muscle controlling the opening and closing of the anus stays tight. When the bowel gets full it empties automatically. **This is called an upper motor neuron type bowel or reflex bowel.**

### Lower Motor Neuron or flaccid hypotonic bowel

If the injury is at or below T12, your bowel will not fully empty, even when stimulated. This is because the damage to the cord has damaged the pathways from the bowel wall into the reflex centre in the spine. Therefore, there cannot be any reflex action. That means that the bowel muscles will not squeeze and anal sphincter muscle remains relaxed. **This is called a lower motor neuron type bowel or flaccid hypotonic bowel.**

If your injury is incomplete or is around T12, you may find that your bowel can take on mixed upper and lower motor neuron type functioning.

### Bowel Routine

The aim of a bowel routine is to allow your bowel to empty at regular intervals, e.g. daily, alternate day, morning or night. We can time your bowel movement to suit you and take into account your lifestyle, care needs etc.

The two most important components of a good bowel routine are diet and timing.

## Diet

How often you empty your bowels and your stool consistency is linked to the quantity and quality of food and drink you take.

A healthy diet including fibre in the form of bran cereals, fruits and vegetables can help keep the digestive process working. Foods high in fibre can absorb and retain liquid and make the stool softer and easier to pass.

Be aware of which foods work for you and which foods don't e.g. some vegetables are gas forming and could prove embarrassing.

Also some foods, alcohol and medicines can alter stool consistency and make bowel movements difficult. Food and drink that affected your stool consistency before your injury, will still affect it.

Make sure you take 2-3 litres of fluid each day to keep your stool soft.

## Food diary

A good way to understand and learn how different foods affect your bowel is to keep a food record. For about three weeks, write down what you eat and drink each day and describe your bowel movements.

## Coffee, Tea, Cocoa or Soft Drinks

Drinks like coffee, tea, cocoa, or soft drinks contain caffeine, a diuretic that may move the fluid out of your body. In fact, diuretics can cause you to lose more fluid than you drink. There is some evidence that caffeine stimulates peristalsis (involuntary muscle movement) in some people. You may want to avoid drinking caffeine drinks or limit how much caffeine you drink.

## Alcohol

Alcohol affects bowel function. It can change bowel habits and reduce appetite, making it hard to stick with the diet part of your bowel routine. It can cause problems with continence and bloating. It may hinder your ability to cope and keep your routine regular. If you're having trouble following your bowel

routine because of alcohol use, please tell your healthcare professional so they can help you.

## Timing

It is important to do your bowel routine around the same time every day or alternate day. It can take several weeks to establish a good routine. If things are not going right do not be tempted to change after a few days or even a week. You should choose a time when you will not be rushing to complete your routine.

Bowels empty more easily 30-60 minutes after a meal or warm drink (when the gastrocolic reflex is stimulated). You can time your routine to take this reflex into account to help you have a bowel movement.

Once your routine is established, stick to it. The bowel is a creature of habit and you may have 'accidents' if you change your routine frequently or change more than one part of your routine at a time.

## Other factors

### Gravity

When you are able to sit for four hours or more in your wheelchair, we will encourage you to get up to the toilet using a shower chair or commode. Gravity helps move the stool down into the rectum. We will offer you a variety of chairs to try. Check your skin regularly as some shower chairs or commodes can be a bit hard.

If you cannot use a shower chair e.g. you have a pressure sore, lie on the side that leaves your dominant hand free.

### Exercise

Physical exercise stimulates bowel function; the more active you are the easier it is for the food to pass through the digestive system. You may find you become constipated during bed rest and you may have to change your bowel medication during this period.

## Smoking

There is some evidence that smoking directly affects colonic function. It is thought that nicotine can stimulate peristalsis (involuntary muscle movement) in some occasional smokers and decrease it in some habitual smokers. For these reasons (and many others), you may want to consider stopping smoking.

## Performing Bowel Care

### Reflexic Bowel

Aim for soft, formed stool that you can pass easily with minimal rectal stimulation. The bowel routine usually starts with digital stimulation or a stimulant medication, e.g. suppositories or enema.

Digital stimulation involves inserting a lubricated gloved finger into the rectum and gently rotating it against the sphincter wall.

### Procedure

- Always keep nails short and neat to avoid puncturing gloves and possibly tearing rectal membranes.
- Move your urinary drainage equipment away from the anal area to avoid stool contamination.
- If possible, sit up. Gravity helps empty your rectum.
- If you don't sit up, lie on your side. Lie on the side that leaves your dominant hand free.
- Check for stool by sliding a gloved well-lubricated finger into the rectum and remove any stool that would interfere with inserting the prescribed suppository or enema.
- If you have a **reflex bowel** use digital stimulation, insert a lubricated suppository or squirt a mini-enema high in your rectum. To keep stool coming, repeat digital stimulation every five to ten minutes as needed, until all stool has passed.
- To make sure the rectum is empty, do a final check with a lubricated gloved finger. You'll know that stool flow has stopped if
  - » no stool has come out after two digital stimulations at least ten minutes apart,
  - » mucus is coming out without stool
  - » the rectum is completely closed around the stimulating finger and you can feel the internal anal sphincter.

## Flaccid Bowel

Aim for firm, formed stool that can be removed manually with ease and doesn't pass accidentally between bowel routines. Bowel care doesn't usually need chemical stimulants because the response would be very sluggish.

People with a **flaccid bowel** should perform a manual evacuation.

## Manual Evacuation

Manual evacuation aims to empty the rectum with the fingers, this is usually described as 'the digital removal of faeces'. This procedure can be carried out either on the bed, commode or toilet.

We will teach you how to do this.

If you do this in bed it is better to lie on the side that leaves your dominant hand free with your uppermost knee bent up slightly and resting over your lower leg.

- Wash your hands.
- Make sure your finger nails are trimmed, as they can puncture the glove and damage the rectum.
- Put on gloves.
- By slowly and gently pushing against the anal sphincters, insert a well-lubricated gloved finger (e.g. K-Y jelly), one to two inches gently into the rectum toward the belly button.
- Use one finger to break up or hook stool and gently remove it from your rectum.
- Continue to remove the stool until you cannot feel or reach any stool in the bowel.

You can help this technique by using your abdominal muscles to bear down. This helps push the stool towards the rectum and is called the valsalva manoeuvre.

## Bowel diary

A bowel diary is the recording of your daily bowel function. You can use it to collect information on your bowel habit. You may find this useful if you are having problems with your bowel routine.

You should record important details such as:

- Any assistive techniques (such as gastrocolic response, Valsalva).
- Stimulation method used (digital or chemical rectal stimulation).
- Exact timing and regularity of your bowel habit (from first stimulation to routine completion).
- Stool amount and consistency.
- Any problems with your bowel, such as unplanned bowel movements etc.
- Comments about your diet (fibre amount).
- Your daily fluid intake.
- Your activity level.
- Your current medication.

All this information will help you during your stay at the local spinal injuries unit and at home. However, when spinal cord injured people are admitted to general hospitals or when they go back to their local community, they can face problems maintaining their routine bowel care. Ward nurses or district nurses might refuse to perform manual evacuation or may want to change this part of your bowel care. A nurse unfamiliar with manual evacuation may need additional information and training.

Different issues that may need to be addressed:

- Only a trained person should perform a manual evacuation.
- If the nurse has never been shown how to do it, you may suggest that they consult their own nurse manager to get the opportunity to learn how to do it.



- If the nurse refuses to do a manual evacuation claiming it is illegal, you must explain that this procedure is not illegal and suggest that they should consult the Nursing and Midwifery Council for Nursing, Professional Code of Conduct or the Royal College of Nursing document entitled Digital rectal examination and removal of faeces.
- If the nurse prefers to change your bowel care, thinking manual evacuation is inappropriate, you should ask them to consult your GP or your local spinal injury unit first.
- You should tell them that inappropriate adjustment or avoidance of your established bowel management programme can have serious consequences for your health and lifestyle.

Ask your local spinal unit to write down the details of your bowel care. It is very important for you to recognise that the nurses believe they are acting in your best interests. You should be able to reassure the nurse that manual evacuation is acceptable and appropriate for your individual care needs. Suggesting a consultation or a phone call with someone with more experience in the field of spinal cord injury is helpful most of the time.

It's a good idea to always have the number of your local spinal unit to hand.

## Medication

### Stimulant Laxatives

These are taken orally and increase bowel contractions and we often use these in the initial stages of the bowel programme.

- Senna: two tablets on alternate days or 10 mls of syrup
- Bisacodyl: 10mgs on alternate days (two tablets).

You should take these drugs eight to ten hours before you want to empty your bowels.

Docusate Sodium: 100mgs up to 500mgs each day in **divided** doses.

## Faecal Softeners or Bulk Formers

Taken orally these are substances which are undigested and absorb fluid thereby increasing bulk and making the faeces soft.

For example:

- Lactulose 10 -15mls once or twice each day
- Fybogel one sachet every day
- Bran
- Benefibre

## Suppositories or Micro-Enemas

These are inserted into the rectum and stimulate the reflex action of the bowel. For example:

- Bisacodyl (irritant)
- Glycerine (lubricant)
- Microlax enema (softener)

**N.B. You should not use large volume enemas regularly as they overstretch the bowel, causing it to lose its tone.**

## Osmotic Laxatives

### Movicol:

For constipation, take 2-3 sachets daily in divided doses. Only take 1 sachet at a time to see if it helps. You can take this for up to 2 weeks.

For faecal impaction– you can take up to 8 sachets per day, for up to 3 days.

You should dissolve each sachet in 125mls water. You can add juice to sweeten the taste.

## Bowel Cleansing Solutions

Picolax which you dissolve in water. You can take another sachet 8 hours later. Usually acts within three hours of the first dose.

Picolax is only used very occasionally and only under medical advice.

## Complications

**Anal fissure** is a tear in the tissue around the anus as a result of passing hard stools or damage to the bowel lining caused by rough manual evacuation. These can be extremely painful; and can cause an increase in spasm and even autonomic dysreflexia. Autonomic dysreflexia is discussed in section 3.

**Constipation** can be caused by a change of diet and routine, low fluid intake, not eating and some drugs such as painkillers, antibiotics and depressants.

If you do not empty your bowel for a long time, the faeces become hard, dry and more difficult to move (impacted).

The symptoms are headaches, feeling sick and feeling full up, not being able to empty the bowel, sweating, increase in spasm, loss of appetite, and sometimes a brown, watery discharge from the anus.

Drinking pear juice may help or try yogurt with seeds or fruit.

With chronic constipation the bowel is blocked but some liquids manage to leak past the blockage, thought to be diarrhoea. This condition is often called 'overflow' and should be treated right away.

**Haemorrhoids** (piles) are varicose veins around or just inside the anus. You may be prone to develop these because of lack of mobility and poor circulation. They are caused or made worse by straining for long periods on the toilet and by rough manual evacuation. If the haemorrhoids are bad, it will complicate the process of bowel management, and can bring on autonomic dysreflexia, in tetraplegia or high paraplegia patients.

Haemorrhoids may also cause rectal bleeding. You should discuss these with your GP or liaison nurse. Surgery may be necessary but there are other treatments that you can try first e.g. haemorrhoid creams.

**Diarrhoea** is an unformed, loose stool, which may cause unplanned bowel movements or 'accidents'. It can cause discomfort, often in the form of abdominal cramps. Diarrhoea can also lead to skin breakdown through faecal burning of the skin by the liquid stool.

You may have to stop taking any laxatives until diarrhoea clears up. You may also have to put yourself on bed rest to try and reduce any skin breakdown from sitting in wet, soiled clothing.

**Flatulence (wind)** is just as embarrassing now as it was before your injury. Odour depends on what you have eaten. Your wind will probably smell bad after you eat food that's high in protein, such as meat, fish, or eggs. If you eat a vegetarian diet, your gas probably won't smell as bad, but you'll have a lot of it.

Excessive bacterial breakdown of bowel contents that is usual for you, or intolerance to dairy products (Lactose intolerance) can also cause bloating. Please discuss this with your GP as medications can help. To help avoid this embarrassing issue you may wish to consider the following points:

### **Your surroundings**

Release gas at appropriate times and places. Good ventilation, deodorant spray and air fresheners can help mask odours.

Push-ups or leaning to the side might help release gas.

### **Think about how you eat**

Excessive gas may be due to swallowing excessive air while you're eating or drinking. Eat your food slowly, chew with your mouth closed, try not to gulp your food and don't talk with food in your mouth.

### **Be aware of foods that can cause gas**

Avoid specific foods from your diet, one at a time, do this until you've learned which, if any cause you to have gas, and then cut down on those foods.

## Check your bowel programme

Increasing the frequency of bowel care may reduce the amount of stool you store in your colon that will produce gas.

Don't try too hard to hold in the gas, it can give you a stomach-ache or headache.

Remember: Passing wind means your digestive system is working. It was ok to pass wind before your injury; it's still ok to pass wind now!

### Bowels

*It took me a long time to get a bowel routine established while I was in hospital. It was one of the most difficult things about my rehab but once established I have had very few problems since.*

# Sexuality after your Spinal Cord Injury

## Introduction

Spinal Cord Injury (SCI) affects to varying degrees the mechanics and sensations of sex and sexuality. Some people think that spinal injury means an end to having a sex life. This section will help you understand the effects of spinal cord injury on your sex life.

## Relationships

Self Confidence – many people with spinal cord injury find the changes in their body takes quite a lot of getting used to. You may have some degree of paralysis, probably use a wheelchair and may have problems with your bladder and bowel control. As time passes you will find that you will gain self-confidence and recover a positive outlook on life. You will find that you become less self-conscious about your body.

## Meeting people

This may be difficult for you if you do not have a stable relationship. Even if you have a partner it can take some time for you both to feel comfortable with each other. Feeling lonely and isolated can be a problem if you are physically unable to get out and about and you may have to think about arranging assistance and transport. It is important for everyone to have relationships, friends and interests. Having a social life, working, and getting out will mean you are more likely to meet people.

## Sensation and Orgasm

Lack of touch sensation in your genital area will mean that having sex and orgasms (if you do have them) will feel different. For some there may be no sensation at all. If you find attempts to stimulate yourself to orgasm are unsuccessful remember that sex is not necessarily just about the physical act of having intercourse or reaching orgasm but of the relationship you have with your partner.

## Male Sexuality

**Erection problems** - Erectile dysfunction (ED), also known as impotence, is when you can't get or keep an erection which is firm enough for sexual intercourse.

Most men with SCI can have erections of some kind either psychogenic, reflex or by using medications or treatments.

**Psychogenic erections** result from sexual thoughts or seeing or hearing something stimulating or arousing. The brain sends messages down the spinal cord to the T12-L2 nerves to stimulate an erection. The ability to have a psychogenic erection depends on the level and extent of your injury.

**Reflex erections** occur when there is direct physical contact to the penis which activates sensory nerves at S2-S4 and then return to the penis via nerve pathways that activate erection. You may experience this when there is direct physical contact to your penis or when you are touched on other parts of your body. A reflex erection is involuntary.

**Treatments** – We will advise you which treatments are suitable for you, but it is up to you to choose the treatment you want to try.

**You may need to try more than one form of treatment before you find the best one for you.**

- **Tablets**

These can help you achieve an erection within 1 hour of taking the tablet. You need sexual stimulation for the tablets to take effect. You cannot take tablets if you are taking nitrate tablets for your heart.

- **Injections**

These involve a single injection into the side of the penis. We will teach you how to prepare the injection and inject yourself. Once you are confident and able to inject yourself, you can do this at home. Your doctor or nurse needs to find the right amount of injection for you. If you have limited hand movement you may need help with the injection.

- **Intra-urethral drugs**

This is the same medication as injections. You insert a small medicated capsule into the urethra (water pipe) using a small plastic introducer. It is not as reliable as self-injection.

- **Vacuum pumps**

This is a plastic cylinder which you place the penis into and then pump air out of the cylinder. This causes the penis to become erect. You then place a special ring at the base of the penis to maintain the erection.

- **Surgery**

Occasionally surgery is an option. This involves placing an implant into the penis which allows you to achieve an erection. This is generally the last option as it is a permanent option and there can be many problems with the implant.

## **Ejaculation**

After your injury the nerve pathways that control ejaculation are disrupted. Ejaculating (climax) can be more difficult to achieve. There is no medical treatment available to improve the ability to ejaculate. Some men find the use of a vibrator may help them ejaculate but it may feel different to what it was like before your injury. Some men may be able to ejaculate through masturbation. Sometimes the semen will backflow into the bladder – this is known as retrograde ejaculation. You may also find your muscle spasms decrease for a few days following ejaculation.

**Ejaculation may cause Autonomic Dysreflexia in T6 and above injuries – please discuss this with your doctor or nurse.**



## Male Fertility

Ejaculation is a complex reflex process. You can use artificial methods of stimulation (medical procedures) to induce ejaculation and retrieve semen (sperm) to get your partner pregnant.

### Facts about sperm

- Men with SCI make normal numbers of sperm, but the number of motile (swimming) sperm can be lower than normal.
- Most of the immotile (non-swimming) sperm are dead.
- Sperm are fragile and rapidly lose their ability to swim.
- Sperm motility does not relate to level of injury, age, or frequency of ejaculation.
- Sperm quality (numbers and motility) can decline within the first few weeks following injury. However it will not continue to decline over the years after your injury.

### Fertility treatments

The spinal clinic runs a fertility clinic on a regular basis. At the clinic we look at ways to achieve ejaculation in order to assess the sperm.

### Vibrator

We can use special vibrators which, in some men can induce ejaculation.

### Electroejaculation

This is when we insert a probe into the rectum and use electrical stimulation to induce ejaculation. We cannot use this method in the clinic if you have sensation in your rectum. However, it can take place in theatre under a light general anaesthetic.

**These methods may cause Autonomic Dysreflexia in T6 injury and above. We will monitor your blood pressure throughout the procedure.**

## What next?

The quality of your sperm will determine which method of fertility treatment is appropriate for you. We will discuss this with you and your partner at your clinic visits.

The most common treatments are –

- Intra-Vaginal Insemination (IVI)
- In-Vitro Fertilisation (IVF)
- Intra-Cytoplasmic Sperm Injection (ICSI).

Intra Vaginal Insemination can take place in the spinal clinic. The others take place in specialised assistant conception units.

### Intra-Vaginal Insemination

This involves directly inserting semen (sperm) into a woman's womb using a special syringe and applicator (a bit like having a cervical smear done). This must be done when the woman is ovulating to increase the chances of fertilisation occurring.

### In Vitro Fertilisation (IVF)

IVF refers to a treatment where fertilisation of eggs takes place in the laboratory. This is by mixing the eggs with your sperm in a sterile dish which are then transferred into the women's uterus (womb).

### Intracytoplasmic Sperm Injection (ICSI)

ICSI refers to a technique in which an egg is injected with a single sperm (from the partner). This procedure takes place in a laboratory. The fertilised egg is then transferred into the women's uterus (womb).

## Female sexuality

Arousal in females can be more difficult following a spinal cord injury and you may find your genitals are very dry even after arousal. Using a jelly lubrication which is water soluble is best as a petroleum based jelly can cause infections. You can use the jelly on yourself for more lubrication, but you can also put it on your partner's genitals or fingers so that when they enter you they will lubricate you at the same time.

## Contraception

SCI does not affect female fertility. Initially after your injury you may find menstruation (having periods) stops but over time you will begin to menstruate again. If you were menstruating before your injury, you will need to use contraception to avoid pregnancy, even if your periods have not returned. Please speak to your GP, family planning nurse or the Spinal Clinic for advice on contraception.

## Pregnancy

As fertility in females is not affected by SCI you will still be able to become pregnant. You may need extra help and advice during and after your pregnancy as it may be more difficult to manage your bowels, bladder, skin, transfers, etc. Please speak to your doctor or nurse in the Spinal Clinic about this.

## Practical advice

### Bladder function

Make sure your bladder is empty before sex as it will make you feel more comfortable and minimise the possibility of incontinence.

- **Female**

If you have a urethral catheter in place you can tape it to the inside of your leg. You can also remove the catheter and replace a new catheter after sex. If using a suprapubic catheter you can tape it to your abdomen.

- **Male**

If you have a urethral catheter you can tape it along the penis but remember to leave enough tubing to allow for an erection. You can also remove the catheter and replace a new catheter after sex. For a suprapubic catheter you can tape it to your abdomen.

If you have a sheath or condom you can either leave it in place but remove the urine bag or remove the sheath completely.

## **Bowel function**

If you follow your bowel programme it is unlikely you will have any accidents during sex. If you are worried, you may wish to empty your bowels a couple of hours before sex. If you have anal sex you will need to make sure your bowels are empty.

## **Autonomic Dysreflexia**

This occurs only in people with a spinal cord injury at T6 or above. You will have been taught the common causes of Autonomic Dysreflexia. Occasionally it can also happen through sex. If you experience any of the symptoms of Autonomic Dysreflexia during sex, you should stop immediately, sit upright if lying down and take your Nifedipine as prescribed.

**If Autonomic Dysreflexia occurs frequently during sex, speak to your doctor or nurse at the Spinal Unit.**

## **Safe sex**

Remember it is still important to practice safe sex to avoid the possibility of sexually transmitted diseases (STD's). Simple precautions such as using a condom will prevent the spread of STD's. It is very important that you discuss safe sex with your partner.

**For further help and advice arrange to speak to the nurses in the spinal clinic.**





### Section 3

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## Staying Fit and Well After Spinal Cord Injury

As you will be aware, your body undergoes a number of changes after spinal cord injury. When muscles don't function, a process called deconditioning takes place which is basically your body becoming accustomed to reduced levels of activity. The reduction in the amount of muscle tissue working in your body has effects both locally in the paralysed limbs and globally throughout your body. This starts within 24 hours of injury and can settle down after 6 to 12 weeks. The good news is that many of these effects can be limited by proper management on your part. We explain these effects below with a number of practical options for you to use to keep yourself as fit and healthy as possible after your injury.

### Cardiovascular System

Your cardiovascular system is your heart, arteries, veins, and blood vessels that are essential to your body's health. This system carries oxygen and nutrients to all of your other body systems. Like the general population, cardiovascular disease is one of the biggest causes of death for people with spinal cord injuries. And like the general population, we recommend regular exercise of moderate intensity for 30 minutes at least, 3 to 5 days of the week to maintain and improve cardiovascular fitness.

People with SCI are generally less active than the general population. This can be due to limited movement, access problems or a lack of knowledge about what activities are available in your community. Over time, reduced levels of activity along with the reduced demands on the heart from less muscle activity causes the cardiovascular system to become deconditioned. This will make you less fit and you may feel that you have little energy and become breathless very quickly with any activity. However, you can avoid this with regular activity and it's never too late to start!

Regular exercise not only keeps you physically fit, your muscles strong and your weight under control, it can also improve psychological wellbeing.

## Weight Management

Initially after your injury you will probably lose weight. This can be due to muscle atrophy (wasting), reduced appetite or intake of food, and your body burning up a lot of energy to help you recover. However, over time many people find that their weight gradually creeps up and possibly more than before your injury. This is because you may continue to eat what you did before your injury but are less active than you were. If you consume more energy through eating than you use up through activity you will start to put on weight.

Increasing your weight beyond what is considered healthy for your height can lead to a number of problems after SCI. Transferring and pushing your wheelchair will become more difficult and you may increase shoulder pain and the likelihood of injury as the load on your arms is increased. Increasing weight in your hips and legs will make leg handling more difficult and may mean that your hips rub against the side or wheels of your wheelchair which can lead to skin issues.

While losing weight after a SCI can be more difficult than before, you can do this through sensible eating and increasing your activity levels. A good balanced diet with lots of fresh fruit and vegetables will not only help your weight, it will help keep your skin, bladder and bowel healthy too.

## Muscle Atrophy and FES (electrical stimulation)

You may have heard the phrase 'if you don't use it you lose it' and this is true with muscles. Just as muscles build up and get stronger with exercise, they shrink and get weaker if you do not use them. Some degree of muscle atrophy (wasting) is unavoidable in paralysed muscles and you will likely see the bulk of your muscles reduce. This can make limbs lighter and easier to handle but it can also make bony parts more



prominent as they will lose some padding which means they are more susceptible to skin problems.

It is possible to exercise paralysed muscles with electrical stimulation (FES) but this won't necessarily change your ability to control your muscles without the stimulator. FES artificially stimulates muscle activity by activating the nerves or fibres within the muscle through pads attached to the skin over the muscle. You have to use it regularly for it to be effective.

Different systems are required for different types of nerve injury i.e. one system for upper motor neuron or high tone paralysis and one system for lower motor neuron or flaccid paralysis. Some people with SCI use FES for aesthetic reasons (e.g. to increase the muscle bulk in the legs as they feel it looks better) but there are a number of health benefits to using FES. FES assisted cycling has been shown to improve muscle bulk, bone density and cardiovascular function.

Currently, there is no funding available through the NHS for FES equipment and it is something that you would have to purchase privately. If it is something that you are interested in, speak to your physiotherapist for details about which system is appropriate for you.

## **Bone Strength**

Your bones need stimulation through muscles pulling on them and weight being put through them to stay strong. Without this stimulation, bones in the paralysed limbs, especially in the legs, start to lose their density and get weaker. This makes them at a higher risk of fracture (break) so you need to be careful when handling your paralysed limbs and how you position them for transfers. The outpatient clinic may arrange for a DXA scan to check your bone density. You can minimise bone density loss by standing regularly or through certain uses of FES (see below).

## Joint Stiffness

The joints and muscles of your limbs will stiffen and may permanently contract if you do not move them regularly through range or stretches. This can happen in both paralysed limbs and limbs with partial muscle function. You are more likely to lose range if you have increased tone or a muscle that pulls in one direction stronger than the one pulling in the opposite way (e.g. strong biceps with weak triceps which will lead to the elbow always sitting with a bend in it). Keeping a good range of movement can help with becoming more independent with your every day activities. If you allow joints to become too contracted, you may lose function and independence.

It is important to follow the advice from your Occupational Therapist or Physiotherapist about splinting or stretching. Sometimes you can have stretching put into your care plan. Staying active will help you maintain range as will regular standing or lying prone (on your tummy) if possible.

## Standing Frames

We will give you one form of standing frame from the spinal unit if it is appropriate for you and your circumstances (e.g. level of injury, space for equipment, someone to help you with standing). This may be in the form of a tilt table, power assisted standing frame, manual standing frame or leg splints (KAFOs) and a walking frame or crutches.

To have maximum benefit from this, we recommend that you stand for a minimum of 30 to 60 minutes, 3-5 times per week. Standing regularly e.g. using a standing frame will help to reduce the amount of bone density loss, minimise muscle spasm, prevent range of movement loss, change the area of pressure over your bottom and open up your stomach area which can help your bladder and bowel function.



If you have any questions about standing, speak to your physiotherapist.

There are also a number of standing wheelchairs ('sit to stand') available that you may be interested to privately purchase.

### How can I exercise?

While in the spinal injury unit you have a substantial amount of equipment and support available to you but it can be a different story when you leave the unit. However, there are still lots of options to staying fit when you leave the unit.

You do not always need ongoing physiotherapy after you leave the unit and there are lots of other ways to keep working on getting stronger and fitter. The biggest difficulty to overcome is motivating yourself to stay active and once you have got this far, many things can be overcome with readily available pieces of equipment and a bit of imagination. Anything that gets you slightly out of breath will be working your heart and is classed as exercise. Here are some suggestions to get you started:

- Get pushing – much like you may have gone for a walk before your injury, push your manual wheelchair. Start on smooth surfaces and build up to bigger distances and slopes. Even if you can only push a chair for 1 meter, if you work at it regularly you will get stronger and be able to push further distances. This will benefit your fitness and arm strength.
- Set yourself up a fitness circuit at home – use resistance bands, bottles of water, tins of beans or anything to add weight to your arm exercises.
- Attend your local gym – many have wheelchair accessible weight and resistance training systems, some even have similar active-passive arm and leg bikes that we use in the spinal unit (e.g. veratrainer).

- If you have reduced hand function, buy some grip aid gloves – you can use these to strap your hands to dumbbells or the handles of weights or exercise bikes. Crepe bandages wrapped around your hand and the object work just as well.
- Find a work out buddy – team up with a friend or relative to assist you with exercising your arms and legs if you can't do it on your own.
- Use your local swimming pool – most pools have hoists to lift you in and out of the pool and many have allocated sessions for people with disabilities. Swimming is a fantastic way to exercise all of your available muscles. Contact your local pool or the Scottish Disability Swimming Development Officer to find out where your local sessions are on 01786 466502 or look at the website [www.scottishswimming.com/index.php?id=86](http://www.scottishswimming.com/index.php?id=86)
- Take up a wheelchair sport – there are a number of wheelchair sports already available and new ones are being developed all of the time. It could be target based sports like archery, shooting or curling, individual endurance activities like wheelchair racing or team based sports like basketball or rugby.
- Get outdoors – there is an increasing variety of adaptive equipment available to get you to places your everyday wheelchair wouldn't be able to: be it water, rocks, sand, hills or snow. Many outdoor centres and parks have equipment available for loan or hire if you can't afford to privately purchase your own.
- Private purchase of equipment – there are a number of companies specialising in adaptive exercise equipment that you can buy to use in your home.

### **How do I find out what is available in my area?**

The easiest thing to do is to call your local sports centre or swimming pool to see what's available or even better, go and have a look at it. Sometimes it's easier to work out what you

can use when you are there and can see the equipment. Fitness staff who haven't worked with someone with a spinal injury before might be nervous working with you at first as they won't want to cause further injury. Your physiotherapist may be able to assist with this and settle their anxieties.

Your local Scottish Disability Sport branch manager will be able to advise you on any exercise groups or sports in your area. The current contacts can be found on [www.scottishdisabilitysport.com/sds/index.cfm/contact/regional-managers](http://www.scottishdisabilitysport.com/sds/index.cfm/contact/regional-managers) or by calling 0131 317 1130.

Here are a few suggestions for websites providing information about adaptive sport and outdoor activities to get you started.

- [www.paralympics.org.uk](http://www.paralympics.org.uk) – Official Team GB Paralympic site with information on Paralympic Sports
- [www.wheelpower.org.uk](http://www.wheelpower.org.uk) – Information about a number of wheelchair sports associations
- [www.backuptrust.org.uk](http://www.backuptrust.org.uk) – charity for people with SCI who run rehabilitative courses in a number of outdoor pursuits as part of their range of services
- [www.equaladventure.org](http://www.equaladventure.org) – provides equipment and training to make the outdoors accessible
- [www.parasport.org.uk](http://www.parasport.org.uk) – information on wheelchair sports nationwide
- [www.youtube.com/user/ParalympicSportTV](http://www.youtube.com/user/ParalympicSportTV) – Internet TV channel with archives and live coverage of disability sport worldwide
- [www.calvert-trust.org.uk](http://www.calvert-trust.org.uk) – run activity breaks for people with all levels of disability
- [www.disabilitysnowsport.org.uk](http://www.disabilitysnowsport.org.uk) – run ski and snowboarding lessons and activity breaks here and abroad regardless of level of injury

If you are unsure about what activities may be appropriate for you, please speak to your physiotherapist or contact the physiotherapy department on 0141 201 2558.

## Autonomic Dysreflexia

Autonomic dysreflexia is one of the most serious life-threatening complications of a spinal cord injury.

It is something that can affect you if your paralysis is T6 or above.

It is vital that you, your family and carers are aware of the:

- possible causes of autonomic dysreflexia
- signs and symptoms
- treatment.

If you do not treat it quickly it can lead to dangerously high blood pressure and become an emergency.

### Why Does It Happen

Autonomic dysreflexia can be caused by any painful stimulus which occurs below the level of injury.

As the spinal cord is damaged, signals cannot pass normally to the brain.

Normally the autonomic nervous system maintains our body homeostasis or balance at an unconscious level. This involuntary part of the nervous system controls the functions of the body which occur automatically i.e. heart rate, blood pressure, appetite, temperature control, etc.

In high spinal injury T6 or above this balance is interrupted.

The body produces exaggerated, abnormal nerve signals which cause problems above and below the level of injury.

### What Are The Signs And Symptoms?

The signs and symptoms can be mild or severe:

- Pounding headache
- Flushing blotchy skin
- Slow heart rate
- Sweating above injury level
- Goosebumps
- Tingling sensation on face or neck

- Stuffy nose
- Anxiety
- High blood pressure

If you have experienced autonomic dysreflexia you will be familiar with the signs and symptoms which affect you and will be able to alert someone quickly.

## The Most Common Triggers

### Bladder irritation due to

- Overfull bladder
- Bladder, kidney stones
- Urinary tract infection
- Blocked catheter

### Bowels

- Constipation
- Distension
- Haemorrhoids

### Skin

- Prolonged pressure
- Pressure sore
- Ingrown toenail
- Deep vein thrombosis
- Fracture

## How do we treat Autonomic dysreflexia?

It is important to find and relieve the cause of dysreflexia. Try to identify the cause from the most common triggers. Locating, treating or removing the cause will allow your symptoms to settle.

Firstly raise your head by sitting up in bed to a maximum of 45 degrees, this allows blood to pool to lower limbs and your blood pressure will fall.

If symptoms persist your doctor may prescribe medication such as sublingual nifedipine 10mg. If symptoms remain despite taking nifedipine contact your doctor.

It is important to have sublingual nifedipine to hand even when out of hospital.

We advise you to carry a medical alert card for the emergency treatment of autonomic dysreflexia.



## Muscle Spasm

The nerves of the spinal cord and brain form a complex circuit that controls our body movements. Information on sensations or processes such as touch, movement or muscle stretch is sent up the spinal cord to the brain. In response, the brain interprets the signal and sends the necessary commands back down the spinal cord to tell your body how to react. The reaction of the body, such as jerking away from a hot object, is a reflex and happens quickly and automatically.

After a spinal cord injury, the normal flow of signals is disrupted, and the message does not reach the brain. Instead, the signals are sent back to the spinal cord and cause a reflex muscle spasm. This can result in a twitch, jerk or stiffening of the muscle. Just about any touch, movement or irritation can trigger and sustain spasms.

Mild spasm is actually quite good in helping to maintain muscle tone, bone strength and reducing osteoporosis. They help maintain circulation and can even assist transfers. However severe spasm is very disruptive to every day activities, wellbeing and mood.

However, spasms can act as a warning mechanism to identify pain or problems below the level of sensation such as:

- Pressure sores
- Ingrown toe nails
- Constipation
- Urinary tract infections
- Over distended bladder
- Fatigue
- Mood changes (excitement, anxiety etc)
- Postural alignment or contractures

## Controlling or Reducing Spasm

- There are several different drugs that your doctor can prescribe to control spasm.
- Staying supple will help reduce spasm. If you or your carer can keep your limbs supple by actively or passively stretching your muscles then they are less likely to contract in response to minor stretches.
- Another way of trying to reduce spasm is to stand on a standing frame or tilt table.
- Lying on your stomach for half an hour a day can simulate the stretch standing gives without the weight bearing.
- Keep as active as you can.
- Maintaining good eating habits can help prevent infections, constipation and sores.
- Reduce how much alcohol you drink and the number of cigarettes you smoke.
- Minimise stress levels.

## Neurogenic Pain

Neurogenic pain ('neuropathic pain') is caused by abnormal communication between the nerves that were damaged by your spinal cord injury and the brain.

In neurogenic pain, it is thought that the brain 'misunderstands' or amplifies the intensity of the signals it is getting from around the area of your injury. This can cause you to experience pain coming from areas of your body below where you have little or no feeling. This is why a person can feel neurogenic pain in an area that otherwise has no feeling. It is often compared to phantom limb pain that patients suffer after amputation.

The pain usually starts a few weeks or months after injury. The symptoms can include pins and needles, burning, stinging or shooting pains.

Even though pain after SCI can be complicated and difficult to treat, there are many treatments available that can help. Understanding your pain, working with your doctor and being open to a variety of treatments will help you manage your pain and improve your quality of life.

### **Patient Story:**

My pain did not start until three months after my injury. It started in my big toe with the feeling that I had a hole in my sock and my big toe had gone through it. Even though I had a complete injury and fully understood this, I still thought that I was getting sensation back in my foot. The feeling was so real but when I took off my shoe my sock was intact.

It is a strange pain as it does not follow any sort of pattern. There never seems to be any particular triggers just some days the pain is better than others.

On a personal level I take medication prescribed by my doctor but I find keeping busy and distracting myself from the pain also helps. One of the most effective distractions I use is taking exercise and using my standing frame.

## Upper Limb or Hands Splints

If you have a cervical injury it is likely that you will have some weakness in some or all of the muscles in your arm (s).

Depending on the level and severity of your injury we may give you splints. These are also known as orthoses.

Splints are individually fitted and can be for the elbow, forearm or hand. Shoulder supports or strapping may also be appropriate. Your occupational therapist will assess and fit any appropriate splints if required. They will also advise you on the appropriate wearing regime.



### What are splints for?

Splints are for providing support to the hand and, or arm. They are individually prescribed and designed specifically to

1. provide support to the hand.
2. maintain range of movement in the joints of the arm and hand, reduce or prevent deformity, contractures and oedema (swelling).
3. prevent changes in the shape of the hand which can happen very gradually.
4. minimise swelling (oedema) in the hand which can cause stiffness and loss of range of movement.

### What are the different types of Splints?

There are many different types of splints. However, the main ones that we may use are listed below.

#### Shoulder Braces

These may help to reduce any (dislocation) in the shoulder joint. Your therapist will give you advice on wearing these.

## **Taping**

This is sometimes an alternative to the shoulder brace at the beginning of rehabilitation.

## **Elbow Splints**

These prevent or reduce elbow flexion contractures (that mean you cannot straighten your elbow).

## **Forearm Splints**

These are also known as T.A.P. (Tone and Positioning) splints.

## **Wrist Supports**

These are usually pre-fabricated neoprene splints with velcro straps to support the wrist leaving the thumb and fingers free. You wear these during the day when moving about.

## **Hand Resting**

These support your hand and wrist joints when resting. These are fitted specifically for you. Depending on level of injury these can be either short (i.e. only supporting the palm, thumb and fingers) or long i.e. designed to support the wrist plus the hand).

After being fitted, you initially wear the hand resting splints for 30 minutes. Over the next 3 to 4 days you should gradually build up the time until you can wear the splints overnight. Generally we recommend that you wear the hand splints for the first 6 months to a year. However each case is individual and your therapist will give you further advice.

## **Small splints**

These come in many shapes, sizes and materials. They can range from pen grips to individual finger supports. These are designed and manufactured as required by the appropriately trained therapists.

## Footcare Advice

Maintaining good foot care and hygiene is important. It is essential that you pay attention to the skin of the feet and your toe nails. If you have 'problem feet' such as thickened, misshapen or difficult to cut toenails, or significant hard skin, you should regularly see a podiatrist (Chiropodist). Before making an appointment make sure that the Podiatrist is registered with the 'Health Professions Council'; sometimes they are listed as 'HPC Registered'.

When caring for your feet at home the following information may be of some help:

### Examining the feet, hosiery and shoes

Examine your feet every day and cover any breaks in the skin or areas developing redness with a dry sterile dressing. Let a health care provider e.g. nurse, podiatrist or doctor know about the break in the skin as soon as possible.

Wear clean socks every day. Seamless socks are best as they are less likely to cause pressure marks to the toes. If you use socks with seams, it is good practice to wear them inside-out preventing the seam from being in direct contact with the toes. Before you put your shoes on check that nothing has fallen inside them that may cause damage to the feet e.g. stones and coins etc.

### Washing the feet

Wash your feet every day with a mild soap along with a wash cloth kept for use on the feet. If the skin tends to build-up in patches, e.g. around the nails and sole of the foot, try using an 'exfoliating cloth' or 'exfoliating gloves' when washing your feet. You should wash your feet thoroughly paying particular attention to the spaces between all the toes. (Never 'steep' or soak you feet as this causes damage in the long term). After washing, rinse your feet and dry well with a clean towel; again paying particular attention between the toes.

## Cutting toe nails

Nails, that don't need to be tended to by a podiatrist, should be cut after bathing. Nail clippers made for this purpose are best. The nails should be cut following the contour of the end of each toe. They should never be cut shorter than the two small channels that they sit in; they are seen at the side of each nail. Ideally, after cutting your nails, use an emery board to remove any rough edges that can tear the nail when socks are put on.

## Care of the skin of the feet

If the skin of your feet is dry it is worthwhile applying an emollient cream such as E45. The best time to do so is just after bathing and drying the feet. Rub the cream in well and avoid applying it between the toes at all times. Immediately after applying the cream put on socks and shoes. Never use any corn, callous or ingrown toenail removing preparations that you can buy in pharmacies. Instead contact your Podiatrist for advice.

If the skin between your toes or around the toe nails becomes moist make sure you are drying them well after each wash. Applying surgical spirit (available from Pharmacies) to the affected areas once a day will help to dry and tone-up the area.

## Selecting footwear

Often the feet can be swollen. Wearing a shoe one size bigger than usual will help to accommodate the swelling.

Ideal shoes have:

- a good shock absorbing outsole
- a broad based, low heel
- a square shaped deep toe area to accommodate your toes.

A plain fronted shoe with no seams particularly around the toes is best. Adjustable straps instead of laces are good as they hold the foot well at the back of the shoe and can prevent it from slipping forward.

## Temperature Control

A normal, healthy human is able to maintain a constant body temperature of approximately 98.6F (37°C) despite the temperature of the environment.

When it is hot, the body sends a signal to the brain via the spinal cord to say the body is too hot. The brain then sends a signal back down the spinal cord and tells the body to cool itself by sweating which evaporates and cools the skin. Blood vessels also expand, bringing more blood to the surface, then the heat from the blood is lost through a process called radiation.

In cold weather, the body sends a signal to the brain via the spinal cord to say the body is too cold. The body senses the lower temperature and our brain tells the body to warm itself by narrowing the blood vessels, therefore reducing blood flow to the skin and reducing heat loss. At the same time goose bumps appear and the hairs stand on end (in hairy people this can help save heat). Shivering also generates heat.

We also have to put more clothes on to warm ourselves up and also warm our environment e.g. turn the heating on.

### After Spinal Cord Injury

After injury it's unlikely you will be able to control your body temperature below the level of your injury and this will be much more affected by changes in environmental temperatures (either indoors or out). The higher the injury, the more likely this will affect you.

### If temperature control affects you:

#### Raised temperature (hyperthermia) ... how to cool down

One of the best ways for a person with a spinal cord injury to cool down is to have a cold wet towel wrapped around the back of the neck. The skin should also be damped down to allow the water to evaporate from the skin, and hence cool the



body down. It's a bit like artificial sweat, but it does work. A cold water spray on the head and shoulders will help reduce the body temperature.

The most obvious way to keep cool is to sit in the shade!

Some of the symptoms of overheating that tetraplegics may suffer from are a headache, nasal congestion, tiredness and reduced concentration.

### **Lowered temperature (hypothermia) ... how to warm up**

If a person gets too cold, they should wear layers of clothing, and drink warm fluids to bring their core temperature back up to normal. If using heaters be careful to avoid skin burning and overheating.

If you become too hot or cold and have problems correcting this; this could lead to serious medical complications. Get medical advice if necessary.



## Section 4

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- Discharge Planning . . . . . 4-1
- Housing . . . . . 4-3
- Education and Employment . . . . . 4-5
- Wheelchair Maintenance . . . . . 4-8
- Spinal Outpatient Clinic . . . . . 4-10
- The Role of the Spinal Nurse Specialists . . . . . 4-13

## Discharge Planning

Discharge Planning starts almost immediately. The consultant sets a provisional discharge date after admission to the Spinal Unit.

As housing issues and benefit enquiries are time consuming it is essential that discharge planning starts as quickly as possible to aid a seamless transition from hospital to home.

**We use goal planning meetings, where you and the team working with you, meet to set goals with target dates. This is the main tool we use to plan and work towards your discharge.**

Once you reach the appropriate level of rehabilitation and you have a suitable house or flat, we may consider you for one of the following:

- Day pass which means a trip outside the unit.
- Step-down Unit which is a fully wheelchair adapted property where family or friends can care for you. (Independent of the unit).
- Overnight pass to an appropriate property.
- An occupational therapist may need to assess any property being considered for an overnight pass or for discharge. They will also identify if any equipment is needed and can be accommodated.

Any training for your family, district nurses or carers needs to take place before we consider any passes.

Before your official discharge date the discharge coordinator or nurse will liaise with your district nurse to make sure all appropriate equipment is in place.

The discharge coordinator or nurse will also make sure:

- Medications (for one week) are ordered for discharge.
- A detailed discharge letter is completed.
- You have an outpatient appointment for the review clinic (normally six weeks).
- You have a minimum one week of supplies.
- You have appropriate transport home.
- Carer agency or district nurses are aware of your discharge and any input (if required).
- You have an appropriate education folder.

### **Post Discharge (after you go home)**

You will need to contact your G.P. to arrange a prescription for your medication and supplies.

Your GP may allow or arrange a company to deliver any appropriate supplies to your house.

You can contact the Liaison team on 0141 201 2550 or 2540 if you have any questions when you go home.

## Housing

Your occupational therapist (OT) will be able to help with any concerns you have accessing your home. Your occupational therapist will discuss your housing situation and if it is appropriate will arrange to carry out an environmental assessment of your home.

This is usually done with an occupational therapist from your local Social Work department.

The purpose of the visit is to:

- Identify if the house can be adapted to meet your needs and the options for adaptation.
- Identify if the house can be accessed in the short term for visits.
- Identify any equipment that you need for both the long term and the short term.

The outcome of the visit could be any of the following:

- The house does not need any changes and is suitable for you going home.
- The house needs minor changes or equipment is needed.
- There are adaptations needed and the appropriate expert(s) needs to be consulted to identify if these changes are possible. If this is the case the community OT will usually advise and assist with the process. This will vary depending on if the property is rented or owned. There are strict guidelines as to what adaptations are funded. These can vary from area to area. General guidelines are available from The Scottish Government website (<http://www.scotland.gov.uk/Topics/Built-Environment/Housing/access/adaptations>). In the case of property which is rented from a housing association or local authority, the individual authorities will need to be consulted on their policies.

- The house cannot be reasonably adapted and re-housing is recommended. If this is the case the OT will assist with identifying your housing needs.
- The house is not suitable for adaptation for long term needs but with equipment can be used for visits or while awaiting re-housing.

### **Re-housing:**

Options for re-housing will depend on your personal circumstances. Usually it will be either renting or purchasing a property.

When renting, for most people, the most appropriate options will be to rent from either a housing association or local authority. Occasionally, when few adaptations are required a private landlord can be considered.

When renting or purchasing, the occupational therapist can give you a housing needs report. You can use this as a guideline in identifying the points to consider when looking at a new property.

When any potential properties are identified, the occupational therapist should assess its suitability for your needs and identify potential adaptations and equipment needed.

## Education and Employment

If, at the time of your injury you are employed or still in education, your occupational therapist will discuss the possibility of returning to either one of these. For many people they see returning to school, university or employment as 'getting back to normal'. Whilst daunting, it is always a positive step.

### Education

Depending on the level of education, we will encourage all students to continue studying whilst they are in-patients and when they feel up to it. The unit will facilitate this by providing time and space for study. This may be delivered by teachers or tutors from your own school or university or from the Education Liaison Service at the Royal Hospital for Children. This may be either one-to-one or on-line.

Should you plan on returning to your original educational establishment on discharge, the occupational therapist will propose a visit to the school or college, if this is geographically feasible.

The visit can serve a number of purposes –

- To meet with staff and provide advice, education and guidance about supporting you back into education. We can provide Information booklets about your level of spinal cord injury as well as contact details for the Spinal Unit.
- An opportunity to review access in and around the building and make recommendations for adaptations, specialist equipment and additional learning support needs.
- To discuss issues such as fire alarms, leisure times, meal times, rest periods and how and where these may be managed.

- To involve the local education authority and make them aware of your needs and allow them to make any necessary changes.
- If possible, you can go on this visit with the occupational therapist. This will give you an opportunity to meet classmates and help build your confidence in a familiar environment.

After the visit, a comprehensive report and action plan will be written and forwarded to all relevant individuals and agencies.

## Employment

For those individuals who are currently in employment your occupational therapist will initially discuss the duties and responsibilities of your post, the environment you work in, e.g. indoors or outdoors, office based etc, your working hours and any other relevant information.

You may have the opportunity to meet with a local Disability Employment Advisor who will tell you what support is available through the Department of Work and Pensions. You could also view the Access to Work information via [www.direct.gov.uk](http://www.direct.gov.uk)

If it is possible to return to your previous job, you should discuss your plans to return with your employer. Your occupational therapist will be happy to meet with your employer to discuss your abilities and any specific needs you may have to allow you to undertake your duties. An application can be made to Access to Work (part of DWP). They will be able to let you and your employer know what support is available in terms of equipment, adaptations and personnel to allow you to return to your job. If needed, the occupational therapists can arrange a site visit to assess the environment for access and equipment. You may be able to attend this initial visit.



Sometimes, if you cannot return to the exact same job – your employer may be able to alter your duties or working pattern to allow you to continue to work.

If you cannot return to your previous post and are unsure of what you would now like to do or be able to do, your occupational therapist will be able to guide you to relevant support agencies. These agencies will be able to help you consider your options regarding employment, re-training or courses that you may be interested in.

## Wheelchair Maintenance

This is something that people do not think about a great deal but if you do not look after your wheelchair there is a chance it could break and possibly leave you stranded.

Below are some wheelchair maintenance tips. These relate to manually propelled wheelchairs but there will be some overlap with powered chairs.

### Tyres

Keeping tyres up to the correct pressure is essential to keep brakes working correctly. Obviously if you have solid tyres this is not an option. If you have inflatable tyres keeping them at the correct pressure will help with the rolling resistance and will also help to keep brakes working effectively.

It is also worth keeping a spare inner tube and tyre levers, either in a bag or keep a spare in the car. A manual hand pump will allow you to put some pressure in the tyre but keeping a small compressor in the car will allow you to inflate the tyre to the correct pressure.

Usually tyres will have a recommended tyre pressure range stamped on the sidewall so if you keep within these limits it will be safe.

### Front Castors

Front castors often get clogged up with hair and various other bits of grease and debris so keeping this kind of dirt from your castors can prolong the life of the bearings. Although the bearings are sealed, if there is debris around the bearing it can stop the wheels rolling efficiently.

To keep the castors clean, you can use a small flat headed screwdriver to remove the debris.

You can also clean out the front castors by using a pair of tweezers or something similar. You can use pointed tweezers to pick out strands of hair one at a time, which will take a bit of time but will also let you get every bit out.

*If you are going to do any wheelchair maintenance in the house, I suggest you put an old towel or something down as you will be surprised how much dirt will come from your chair.*

This does not cover power chairs, but a lot of the principles are the same.

### **General Maintenance**

Look over your wheelchair to make sure that it is in a good condition: upholstery is not worn or torn, seat belts are present and functioning, and the wheelchair is clean. Check the frame of your chair for any signs of wear, rust or loose connections.

## Spinal Outpatient Clinic

The spinal injury clinic at the Queen Elizabeth University Hospital, Glasgow provides regular lifelong follow-up care following your spinal cord injury.

When you go home your clinic appointments for review will usually be

- 6 weeks
- 3 months
- 6 months
- Then once a year

If you are having any problems we may see you more often.

At your first clinic appointment the medical staff, usually your consultant will review how you are doing.

At your other appointments you may see either a doctor or nurse. You may also see the occupational therapist who will review your wheelchair and seating.

### Nurse-Led Clinics

We have nurse-led clinics which means if you attend the following clinics you will see an experienced spinal injury nurse rather than a doctor. Your appointment involves:

- A halo check
- Spinal review (with the exception of the first 6 week appointment)
- Discussing sexual function
- Advice about skin care
- Acupuncture or TENS
- Intrathecal pump refill

If you have any medical problems, or want to see a doctor, we will arrange this.

## Drop – In Clinics

We also operate a drop-in clinic. You can see a nurse at short notice if you have problems with your skin, bladder, bowels or other minor complaints relating to your spinal injury.

We are also happy to provide advice over the telephone. For advice or to arrange a time to drop into the clinic please contact us on 0141 201 2563 (Monday to Friday, 8.30am – 4.30pm).

If you need to see a doctor, we will arrange an appointment for you.

## Specialist Clinics

We run the following specialist clinics with medical staff. We will arrange appointments for you at these clinics if appropriate.

- Spasm
- Urology
- Lumbar spine
- Cervical spine
- Respiratory
- Hand
- Urodynamics (bladder pressure testing)
- Fertility

## Your Appointment

What to bring with you:

Your appointment letter

A note of your current medication

## **Your appointment:**

We will make every effort to make sure we see you at your appointment time, however:

Some patient appointments may take longer than expected.

The doctor can sometimes be called away to an emergency in the ward.

We will tell you about any delays.

## **Cancelling or Changing Your Appointment**

If for any reason you cannot keep your appointment, please let us know as soon as you can by telephoning 0141 201 2538.

This will allow us to reschedule your appointment and give your appointment to another patient.

**Please let us know if your details change i.e. new address, change of name, telephone number etc.**

## **Transport**

If you need patient transport, please call the Scottish Ambulance Service on 0300 123 1236. They will ask you a series of assessment questions to determine your need.

If you no longer need the ambulance or car, please call 0800 389 1333, as soon as possible, before your appointment date and tell them your name, address, phone number, date of appointment and hospital clinic you are attending. This phone number is an automatic answer machine. (They do not cancel your appointment - this is your responsibility if you are not attending.)

Please note they will only transport your escort or companion if absolutely necessary for your medical need.

## **Important Telephone Numbers**

Spinal reception – 0141 201 2538

Spinal outpatient clinic – 0141 201 2563

Spinal liaison office – 0141 201 2550 or 2540

## The Role of the Spinal Nurse Specialists

The Spinal Nurse Specialists provide life long follow up, care, support and advice to all patients who go home from the Spinal Unit who have suffered a spinal cord injury with some degree of spinal cord damage.

Within the first week of your admission, we tell your community district nurse by both telephone and letter about your spinal cord injury. By doing this it allows the complex discharge planning process to begin. It also builds a good working rapport with colleagues in the community who may be involved in your care once you go home.

We attend your inpatient goal planning meetings and discharge case conferences which on occasion due to location can be done by tele-medicine links.

We will invite your district nurse to all your goal planning meetings and if they are unable to attend update them by telephone afterwards.

Our aim is to link you, the patient, to the Spinal Unit multi-disciplinary team and community setting.

Upon discharge, if you have no spinal cord damage you will receive a follow up telephone call within two weeks of going home.

In addition we provide support, education and information to your family, carers and other professionals who may be involved in your care. This also includes working jointly with other hospitals, nursing homes and community professionals.

We help in the management of:

1. Bladder and bowel care.
2. Skin care and pressure sore management. This involves working jointly with the occupational therapy department who deal with patients' cushions, seating and general wheelchair assessments.

We offer post-discharge visits to all patients throughout Scotland, including the Islands, within four weeks of their initial discharge home. In doing so, we aim to promote a safe and smooth patient transfer from hospital to home or any other community placement.

You, your family or other health professionals can also request further visits from us. By offering this service it hopefully reduces the risk of long term complications and re-admission to hospital.

We run Outreach Clinics at:

- Aberdeen 5 times per year
- Arbroath 3 times per year
- Dumfries 2 times per year
- Borders 2 times per year
- Huntly Once per year
- Inverness 4 times per year
- Lothian monthly

By providing these clinics it allows you to attend a spinal injury review appointment locally with the benefits of reduced travel time and costs. When arranging the clinics we try and give patients a choice of appointment times that may fit into their daily routine and bowel routines etc.

If for any reason you are admitted or transferred to your local hospital for treatment we can also provide support, advice and training to local professionals. This includes us carrying out visits, and providing advice and guidance. We also supply information regarding your care by both telephone and information booklets. By doing this we aim to reduce the risk of you developing complications during your admission.

All patients when discharged are given direct access to ourselves both by telephone and email.

We do have a 24 hour telephone answer machine but this is for non-emergency calls. For any emergencies please contact your GP or when surgeries are closed contact NHS24 on 111.





## Section 5

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- Information about Driving . . . . . 5-1
- Transport. . . . . 5-10

## Information about Driving

For many people, using transport or being able to drive after a spinal cord injury can be a daunting thought. However, the freedom of a car is more of an essential than a luxury for most wheelchair users. So, for those who are considering it, here are the most frequently asked questions and the answers we are able to give here in the unit. You can get more in-depth information from the Scottish Driving Assessment Centre in Edinburgh or from the Motability Scheme (contact details at the bottom of this section).

When thinking about returning to driving, you must consider a number of points and the majority of people need a referral to the Scottish Driving Assessment Centre in Edinburgh. They will assess your ability to control a car. This is not a driving test.

### Do I have to let DVLA know about my injury?

#### Driving License

Yes, if you have had a spinal cord injury you are required by law to tell the Driving and Vehicle Licensing Agency (DVLA).

You can do this by writing a letter. They will usually respond in writing to you and may send you out further medical forms for you to fill in to gain a clearer picture of your injury. You must complete a Confidential Medical Information Questionnaire (form G1) which will tell the DVLA of any details relating to your injury. As part of the G1 form there is an additional form D497 which is a Declaration of Special Controls Required.

This section has a number of tick boxes that list types of controls that you might need to allow you to drive. On some occasions they may contact your consultant or GP for further information. In some instances DVLA may request you send your license to them to allow it to be amended. If you know you are going for a driving assessment it is useful to mention this in your initial letter, as you need your licence with you at your assessment.

More information about driving with a disability is available on the Directgov website: [www.direct.gov.uk](http://www.direct.gov.uk)

### As a paraplegic do I need to go for a driving assessment?

If your injury has left you with complete paraplegia, with no other injuries, you do not need a formal assessment. As you are unable to operate the pedals of a manual drive car you will need to drive an adapted car, normally an automatic with hand controls. There are numerous different styles of hand controls available depending on your balance and dexterity.

The most common style of hand controls is a push and pull accelerator but even then there are many configurations.

If you are entitled to a car through the Motability Scheme you can have input as to what style of hand controls you can have fitted, within reasonable cost of course.

Steering aids (steering balls or grips) also come in various designs and it is a matter of finding out which one is most suitable for you.

Converting your vehicle from manual to hand controls normally costs about £500 though prices do vary and there are a number of different types available.

There is now a scheme with motability that can assist with costs. More information is available on the website [www.motability.co.uk/cars-and-wavs/adaptations-and-adjustments/adaptations-prices](http://www.motability.co.uk/cars-and-wavs/adaptations-and-adjustments/adaptations-prices)

A referral to the Scottish Driving Assessment Centre may be helpful to try the different controls available. It may also be helpful to have a driving lesson with a qualified instructor (BSM have adapted vehicles available for lessons) to give you the opportunity to practice the controls and improve your confidence. Neither of these are essential or legal requirements, but we would recommend them. Spinal Injuries Scotland has a list of hand control suppliers that they can either email or send out by post if required.

## Is using hand controls difficult?

Driving using hand controls can be worrying at first but most people adapt to it fairly quickly.

For some people balance is the one thing that they find slightly more difficult to adapt to but this varies between individuals and their level of injury.

Steering aids on the steering wheel can help especially when turning corners but again the more you do it the more you get used to it. Positioning of the steering aid can also make a difference so make sure if you are having a steering aid fitted it is in a position that suits you.

Some people prefer to have the steering aid located at approximately between the ten and eleven o'clock position and others prefer it between seven and eight o'clock.

This is a personal preference but can make a huge difference to confidence when driving.

## As a Tetraplegic will I be able to return to driving?

This is dependent on the level and severity of the injury. As you have paralysis of your lower limbs and partial paralysis of your upper limbs you will need to go for a driving assessment. The purpose of the assessment is to establish if you have the ability to control the car and to identify the adaptations that are required to help this, not your driving ability. Your consultant and occupational therapist will make the referral whilst you are in hospital. If you are discharged your consultant can still make the referral or you can ask your GP to make one.

## I can't transfer from my wheelchair to a car seat. Does this mean I cannot drive?

If you are unable to transfer in and out of a car independently, there may be equipment available that will assist you. This can be assessed at the Driving Assessment Centre. If you cannot transfer you will need to consider a vehicle that can be

converted to allow you to drive from your wheelchair. These vehicles can be expensive. Although grants are available through the Motability Scheme, there are limitations and specific criteria to consider. These details are available on the Motability website. [www.motability.co.uk](http://www.motability.co.uk)

### What happens during the assessment?

The initial part of the assessment is an interview. This is to get basic details about you and to gain further information about your injury and your current health. It involves a basic eyesight test and physical assessment. The test will then establish if you have any cognitive problems.

The next part involves transferring into something called a 'Static Rig'. This is basically the dashboard and driving controls of an Alfa Romeo car. The rig can be converted to accommodate numerous steering controls with adjustments made to the power steering. The rig assesses reaction times and average strength used in steering and braking.

If you have been successful in achieving average times during your assessment and the first part of the assessment went well, you may then progress into an adapted vehicle to allow the assessor to confirm your abilities. It also gives you a chance to 'have a go' at driving. The drive starts off around the grounds where the assessment is taking place, followed by a short trip on nearby roads.

When you complete the assessment you will be advised at the time, and in writing on the adaptations that you need to allow you to safely drive, and possibly the type of car that you may need. If the test hasn't gone as well as you hoped there is always the opportunity to go for a further assessment in the future. It isn't a matter of one test, one chance.

## **My injury is incomplete, do I have to go for an assessment?**

Probably. If you have an incomplete tetraplegia then we recommend a driving assessment. This is because you have weakness in all 4 limbs and again it is to make sure you can safely control the car. The recommendation may simply be an automatic vehicle with ultra light steering. If you have an incomplete paraplegia, the need for an assessment depends on the level of weakness and any sensory deficit in your lower limbs.

## **During my injury I acquired a head injury, how soon can I return to driving?**

This depends very much on the severity of the head injury you have had and if you had any surgery to treat it. If you are experiencing black outs, memory problems, seizures, visual disturbances etc then it may be too soon to have a driving assessment. Depending on the severity of your head injury and surgery you may have to wait 12 months to get a driving assessment. It's best to get advice from your consultant or occupational therapist about this.

## **I didn't drive before my injury, how do I get my license?**

You must have a provisional licence before you can have an assessment. (If you don't hold one you will need to get one). If it is likely that you will need an adapted vehicle to have lessons, you may also need an assessment to establish the type of adaptations required. Many of the larger driving schools have automatic vehicles converted with hand controls which you can access for lessons. Otherwise, you may have to provide your own dual control, adapted vehicle. You may have to fund these adaptations or there are grants that you can apply for through the Motability scheme.

## **I'm 16 years old, do I have to wait until I am 17 to apply for my provisional license and have driving lessons?**

No, you may apply at 16 years old. You may also be eligible for a grant to assist with the cost of the lessons and conversion of your vehicle.

## **I don't live in Edinburgh, can I still have a Driving Assessment?**

Yes. The Scottish Driving Assessment Centre is based at The Astley Ainslie Hospital in Edinburgh. As the Centre covers the whole of Scotland it does have a waiting list, so you may wait a number of weeks for your appointment.

## **Driving Assessment Centre**

Returning to driving for many is easier than you think. The Centre is there to encourage disabled drivers back behind the wheel, hopefully increasing their independence and quality of life. If for whatever reason driving is no longer an option for you the Centre can provide advice and guidance about adaptations, transfer options, adapted vehicles and a whole variety of other information including grants for adaptations and driving lessons.

## **I do not drive and cannot transfer out of my wheelchair. What are the options for transport for me?**

- Public transport – buses and trains
- Taxi – hackney taxis have ramps
- Dial-a- ride
- Wheelchair adapted vehicle etc

## Other useful points to note

If you lease a car through the Motability Scheme you automatically get breakdown cover from one of the major breakdown organisations.

If you don't have a Motability car, tell your breakdown company about your disability. They will add this to the information they already keep for you. This does not mean that you will be first to be attended to in the event of a breakdown but they will try and prioritise dealing with you.

## Insurance

There should be no difference to insurance for cars fitted with hand controls. Hand controls are not seen as an adaptation to the car but it is good practice to let your insurance company know that you are driving with hand controls.

If you lease a car through the Motability scheme, you will not accrue any 'No claims discount' as you would do on other regular insurance policies. This would affect the cost of your insurance if you choose to leave the Motability scheme and buy a car privately. Royal and Sun Alliance, the insurance company for Motability should be able to provide details of your insurance claims, if any, to an insurance company but they may charge you for this service.



## Scottish Driving Assessment Centre

The Centre provides practical and independent advice and assessment to disabled drivers and passengers.

Marlene MacKenzie

Service Manager

Scottish Driving Assessment Centre

Astley Ainslie Hospital

133 Grange Loan

Edinburgh EH9 2HL

marlene.mckenzie@nhslothian.scot.nhs.uk

0131 537 9100 or 9192

## Motability

If you receive either the Higher Rate Mobility Component of Disability Living Allowance (HRMC DLA), the Enhanced Rate of the Mobility Component of Personal Independence Payment (ERMC PIP), the War Pensioners' Mobility Supplement (WPMS) or the Armed Forces Independence Payment (AFIP) you may be eligible to join the Motability Scheme.

Check out their website for more information.

[www.motability.co.uk](http://www.motability.co.uk)

0845 456 4566

## DVLA

Drivers Customer Services

Correspondence Team

DVLA

Swansea

SA6 7JL

## **Driver Licensing Enquiries**

Telephone: 0300 790 6801

Fax: 0300 123 0784

Or

## **Drivers Medical Enquiries**

DVLA

Swansea

SA99 1TU

## **Driving and medical issues**

### **Drivers Medical Enquiries**

Telephone: 0300 790 6806

Fax: 0845 850 0095

# Transport

## Public Transport

If you are using public transport, it's worth contacting the transport operator before you travel to make sure they are able to offer the assistance you need.

You can get more information from [www.gov.uk/transport-disabled](http://www.gov.uk/transport-disabled)

## Taxis

Taxi and private hire companies can provide wheelchair-accessible vehicles if you let them know when you book a vehicle.

## Flying

This section is to tackle some of the anxieties you may have about flying. It will highlight some of the things that you might come up against when you do fly.

If you intend flying, make sure that your airline is fully aware of your requirements. This will allow them to make the necessary arrangements and provide any assistance you might need when you arrive at the airport. It also allows them to plan for your arrival at your destination.

It can be important to take your own cushion with you. This is not essential for in-flight comfort, however if you do experience an issue with the airline handlers misplacing your own chair, you will at least have your own specific cushion to place on any chair they provide whilst they locate yours. It is extremely rare for a wheelchair to be misplaced on a flight, however as always it is best to be prepared!

Cabin crew and airline staff are very helpful and will do their best to make sure the various stages of your journey run as smoothly as possible. They may offer you a choice of seat on the aircraft (however you may not be able to sit near the emergency exits).

## What help is available at airports:

- facilities to get assistance at designated arrival points, such as at terminal entrances, at transport interchanges and in car parks
- assistance to reach check-in
- help with registration at check-in
- assistance with moving through the airport, including toilets if required
- help with getting on and off the plane
- free carriage of medical equipment and up to two items of mobility equipment
- a briefing for you and any escort or companion on emergency procedures and the layout of the cabin
- help with stowing and retrieving baggage on the plane
- assistance with moving to the toilet on the plane (some planes will have an on-board wheelchair)
- someone to meet you off the plane and help you reach connecting flights or get to the next part of your journey

Once you arrive at the airport, head to the check in desk, even if you have checked in online. It is essential that you have your wheelchair tagged for your destination airport. This is where you have to think carefully especially if you are going via another airport. If you require your chair at the connecting airport make sure that it is tagged to go to that airport and not your final destination airport as your chair will go directly to that airport and you will not see it at your connecting airport.

## **Holidays**

*“I was a bit nervous of flying for the first time so I did it with some friends along for support. Since then I have taken numerous flights on my own and always found the staff at the airports to be more than helpful”.*

More information is available from:

[www.direct.gov.uk/en/DisabledPeople/  
TravelHolidaysAndBreaks/GettingThere/DG\\_4017242](http://www.direct.gov.uk/en/DisabledPeople/TravelHolidaysAndBreaks/GettingThere/DG_4017242))



## Section 6

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## Operations, Appointments and Tests

Use this page to keep an up to date record of any tests you have, any operations or any time you are in hospital. If you wish, hospital staff will help you fill it in.

Procedure	Date and Location	Reason	Results

# Equipment list

Equipment	Provider

If you experience problems with any of the equipment contact the provider directly.













## Glossary

These pages explain words that we use in your booklet.

Word	Explanation
<b>Ankle - foot orthosis</b>	AFO Brace supporting the forefoot and preventing plantar flexion or 'foot drop'.
<b>Ambulation</b>	A walking motion, often aided by braces and or crutches.
<b>Ankylosis</b>	Loss of mobility in a joint caused by bony deposits of calcium.
<b>Ankylosing spondylosis</b>	A degenerative disease of the spinal column, especially one leading to fusion and immobilisation of the vertebral bones.
<b>Anoxia</b>	A state of almost no oxygen delivery to a cell, resulting in low energy production and possible death of the cell.
<b>Anticholinergic</b>	A type of drug often prescribed to reduce spasms of smooth muscle, especially of the bladder.
<b>Anticoagulants</b>	A drug therapy used to prevent the formation of blood clots that can become lodged in cerebral arteries and cause strokes. Also used to treat blood clots in the leg or lung.

Word	Explanation
<b>ASIA impairment scale</b>	<p>This scale describes a person's functional impairment as a result of their spinal cord injury</p> <p>A = Complete. There is no movement or feeling in the lowest sacral segment</p> <p>B = Incomplete. There is feeling but no movement</p> <p>C = Can move more than half the main muscle groups below the level of injury. Muscles having poor to medium strength</p> <p>D = Can move more than half the main muscle groups below the level of injury. Muscles having medium to good strength</p> <p>E = Normal. There is full movement and feeling</p>
<b>Ataxia</b>	<p>A problem of muscle co-ordination due not to weakness, rigidity, spasticity or sensory loss, but in-coordination of movement.</p>
<b>Atrophy</b>	<p>The decrease in muscle mass as a result, of a SCI, or a neurological lesion and prolonged immobilisation.</p>
<b>Autonomic Dysreflexia (AD) or (Autonomic hyperreflexia)</b>	<p>An exaggerated response by the nervous system to various stimuli below the level of injury in SCI lesions about T6. A potentially dangerous reaction (sweating, chills, high blood pressure, severe headache). Untreated AD can lead to a fit or even a stroke.</p>

Word	Explanation
<b>Axon</b>	The nerve fibre or process that carries a nerve impulse from the nerve terminals in the body back to the nerve cell.
<b>Brown-Sequard syndrome</b>	An incomplete spinal cord injury wherein half of the cord has been damaged. There is spastic paralysis on the same side as the lesion and loss of pain or heat sensation on the opposite side of the lesion.
<b>Catheter</b>	A fine tube that can be inserted into the body e.g. a urinary catheter is inserted into the bladder.
<b>Catheterisation</b>	The process of inserting a catheter e.g. urinary catheterisation is the process of introducing a catheter into the bladder
<b>Cauda Equina</b>	The cauda equina carries nerves which control the bladder and bowel. This is at the end of the spinal cord.
<b>Central cord Syndrome</b>	Trauma to the centre part of the cord only, affects upper limbs more than lower limbs.
<b>Cerebrospinal Fluid(CSF)</b>	The circulating clear fluid that bathes the brain and spinal cord, protecting it from shock.
<b>Cervical</b>	The portion of the spinal cord in the neck area (C1 – C7).
<b>Chronic</b>	A condition that is continuous or persistent over an extended period of time, not easily or quickly resolved. The opposite of acute.



Word	Explanation
<b>Clonus</b>	Involuntary movement of rapidly alternating contraction and relaxation of a muscle.
<b>Central Nervous System(CNS)</b>	Nerve tissue within the brain and spinal cord.
<b>Colostomy</b>	A surgical procedure to facilitate emptying the bowel through the wall of the abdomen.
<b>Complete injury</b>	Generally, a spinal cord injury that cuts off all movement and feeling below the lesion site. (Also known as ASIA impairment Scale 'A').
<b>Coccyx</b>	Commonly referred to as tail bone. It is located at the bottom of the spinal column.
<b>Cystography</b>	An examination of the interior of the bladder. This involves injecting a radio opaque solution (dye) to allow x-ray images to be taken.
<b>Contracture</b>	A joint that has stiffened to the point that it cannot be moved through its normal range.
<b>Crede</b>	Using the hands to push on the lower abdomen to express urine.
<b>Cyst</b>	A cavity that fills with fluid (See syringomyelia).
<b>Cystogram</b>	An x-ray of the bladder to show reflux (backward) flow of urine back up to the kidneys.

Word	Explanation
<b>Cystoscopy</b>	A direct examination of the bladder using a cystoscope (a small flexible tube) inserted in the urethra.
<b>Decubitus ulcer</b>	A skin sore caused by unrelieved pressure.
<b>Deep Vein Thrombosis (DVT)</b>	Reduced blood flow in the lower extremities after spinal cord injury; can lead to blood clots (DVT's) that can, in turn, lead to pulmonary embolism (blocked blood vessels in the lung that can be fatal). Treated with anticoagulant drugs and compression stockings.
<b>Demyelination</b>	The loss of nerve function due to the loss of nerve insulation called myelin. Common in multiple sclerosis and spinal cord injury.
<b>Dermatome</b>	Area of skin that is served by one spinal nerve.
<b>Digital stimulation</b>	A technique for manually or mechanically triggering a bowel movement.
<b>Diuretic</b>	Medicines or substances that cause the kidneys to excrete a larger volume of water from the body. For example, alcohol, coffee, tea, and chamomile tea.
<b>DREZ</b>	Short for dorsal root entry zone procedure, a surgical method of pain treatment that precisely cuts nerves in the dorsal root of the spinal cord.

Word	Explanation
<b>Dura Mater</b>	The tough, outermost membrane surrounding the spinal cord and brain.
<b>Dysphagia</b>	Having trouble eating and swallowing. Requires a speech and language therapy assessment.
<b>Dyssynergia</b>	Failure of muscle co-ordination especially in the bladder.
<b>Electro-ejaculation</b>	A method of obtaining viable sperm from men who are unable to produce a sample by other means; this involves stimulating the seminal vesicles using an electrical probe in the rectum.
<b>Electromyogram (EMG)</b>	An examination that records the electrical stimulation of the muscular contractions and helps determine the origin of a motor deficiency.
<b>Embolism</b>	The abrupt obstruction of a blood vessel by a blood clot, an air bubble or any other foreign body (embolus) not normally found in the blood.
<b>Excitotoxicity</b>	Excessive release of neurotransmitters, causing damage to nerve and glia cells.
<b>Flaccidity</b>	The absence or decrease in muscle tone.
<b>Functional electrical stimulation(FES)</b>	Application of low-voltage currents to enhance the function of paralysed muscles.

Word	Explanation
<b>Foley catheter</b>	A type of bladder drainage system that remains inserted in the bladder and drains to a storage bag.
<b>Freidrich's Ataxia</b>	An inherited, progressive dysfunction of the cerebellum, spinal cord and peripheral nerves.
<b>Glia</b>	Also called neuroglia; the supportive tissue of the nervous system, including the network of branched cells in the central nervous system (astrocytes, microglia, and oligodendrocytes) and the supporting cells of the peripheral nervous system (neurilemma and satellite cells).
<b>Growth factors</b>	Small proteins in the brain and spinal cord that are necessary for the development, function and survival of specific types of nerve cells.
<b>Halo-vest</b>	A device which allows traction of the cervical vertebrae (the neck) while immobilising it in the right position.
<b>Harrington rods</b>	Metal rods commonly placed under the skin along the spinal column for support after spinal cord injury.
<b>Hemiparesis</b>	Reversible weakness on one side of the body.
<b>Hemiplegia</b>	Paralysis on one side of the body.
<b>Heterotopic ossification</b>	Bone deposits around the hips and knees and other connective tissue.
<b>Hydronephrosis</b>	When the kidney is so full of urine that it is functionally impaired.

Word	Explanation
<b>Hyperbaric Oxygen Therapy</b>	A system of delivering pressurised oxygen to help treat decompression sickness (the bends), smoke inhalation, air embolism and other conditions.
<b>Hyperhidrosis</b>	A condition characterised by abnormally increased sweating or perspiration.
<b>Hypoxia</b>	A decrease in the amount of oxygen found in the blood and subsequent level of oxygen in the tissue caused by hypoventilation and reduced cardiac output.
<b>Incontinence</b>	The involuntary elimination of urine or faeces.
<b>Ileostomy</b>	A surgical procedure that opens the ileum (small intestine) to facilitate removal of faecal material through the abdomen.
<b>Incomplete injury</b>	Generally, a spinal cord injury with preserved sensory or motor function below the lesion level. (ASIA Impairment scale B, C, D).
<b>Indwelling catheter</b>	A flexible tube that is left in the bladder and used to empty the bladder on a regular schedule; used for self catheterisation.

Word	Explanation
<b>Ischial</b>	That part of the iliac bone which is located beneath and behind the pelvis, under the buttocks.
<b>Kidney-Ureter-Bladder (KUB) Radiography</b>	Abdominal X-rays of the abdomen to detect abnormalities such as kidney stone, tumours or other obstructions.
<b>Laminectomy</b>	An operation to relieve pressure on the spinal cord.
<b>Laryngotomy</b>	An operation which consist of making an incision in the larynx. It allows intubation to ensure respiration by mechanical means.
<b>Lesion</b>	The site of injury or wound to the spinal cord.
<b>Lower motor neurons</b>	Nerve fibres that originate in the spinal cord and travel out of the central nervous system to the muscles. An injury to these nerves can affect muscle, bowel, bladder and sexual functions.
<b>Lumbar</b>	The thickest section of the spine; the lower back below the thoracic area.
<b>Magnetic Resonance Imaging ( MRI)</b>	More precise than computed tomography (CT scanning), MRI scanning consists of placing a person within a cylinder that produces a strong magnetic field. This examination allows the reconstruction of images of body layers using a computer. You cannot have a MRI if you have a pacemaker.

Word	Explanation
<b>Methylprednisolone</b>	A steroid given to people with spinal cord trauma within eight hours of injury, a neuroprotective that may help increase the chances of functional recovery.
<b>Mitrofanoff procedure</b>	This operation creates a conduit in the navel or lower abdomen connecting the bladder to a stoma, allowing intermittent catheterisation for quadriplegics and women who have trouble accessing their urethra.
<b>Motor neuron</b>	A nerve cell that carries information from the central nervous system to the muscles.
<b>Myelin</b>	White, fatty insulating material on nerve cells that helps rapid conduction of nerve impulses. Loss of myelin accompanies MS, spinal cord injury and other neurological conditions.
<b>Necrosis</b>	A form of cell death resulting from anoxia trauma or any other form of irreversible damage to the cell; involves the release of toxic cellular material into the intercellular space, poisoning surrounding cells.
<b>Neuron</b>	The main cell of the brain and nervous system.
<b>Neurogenic Bladder</b>	A lack of bladder control due to a brain, spinal cord, or nerve condition.

Word	Explanation
<b>Neuroprosthesis</b>	An implanted functional electrical stimulation device that allows paralysed people to do things such as breathe off a ventilator, grasp a key, stand for a transfer, empty the bladder.
<b>Occupational therapy</b>	The process by which people with paralysis are taught to maximise their independence in the real world by use of assistive technology, management of daily living activities and maintenance of health.
<b>Oedema</b>	An excessive accumulation of fluid in tissue spaces or a body cavity.
<b>Orthosis</b>	An external device that supports the body and limbs or assists motion. For example, glasses, crutches, wheelchair.
<b>Orthostatic hypotension</b>	Pooling of blood in the lower extremities: combined with lowered blood pressure in people with spinal cord injury, results in light-headedness, numbness and or pallor.
<b>Osteomyelitis</b>	Infection of underlying bone, often related to decubitus ulcers.
<b>Osteoporosis</b>	Loss of bone material, common after paralysis and inactivity.
<b>Ostomy</b>	An opening in the body to drain the bladder (cystostomy), to remove solid waste (colostomy or ileostomy) or allow passage of air (tracheostomy).



Word	Explanation
<b>Paralysis</b>	Injury or disease to a person’s nervous system can affect the ability to move or feel: this reduced motor or sensory ability is called paralysis.
<b>Paraplegia</b>	Loss of function and paralysis in the legs which translates as a loss of strength.
<b>Percussion</b>	A series of rapid, sharp taps against the abdominal wall at the level of the bladder using the inside edge of the open hand, in an effort to stimulate urination.
<b>Peripheral Nervous System (PNS)</b>	Nerves in the body away from the brain and spinal cord: they have the ability to self-repair that the central nervous system nerves do not.
<b>Peristalsis</b>	Rhythmic muscular contractions of the digestive tract.
<b>Phrenic nerve stimulation</b>	Application of an electrical signal to the phrenic nerve in the neck or the chest, which controls the diaphragm and therefore breathing.
<b>Physical therapy</b>	The process of regaining maximum body function and physical abilities.
<b>Prognosis</b>	Prediction or forecast regarding the course of a disease.

Word	Explanation
<b>Postural hypotension</b>	Reduced muscle and blood vessel activity in the lower extremities, which causes blood to pool in the legs of people who are paralysed. Reduced blood pressure can cause light headedness. Wearing elastic stockings, or an abdominal binder is recommended.
<b>Pressure sore</b>	A skin breakdown due to unrelieved pressure.
<b>Priapism</b>	An erection that last for several hours or more, a dangerous side effect of certain drugs that improve erectile dysfunction.
<b>Prosthesis</b>	An appliance or device used to replace a limb, a part of an amputated limb, or an organ that is severely damaged or destroyed.
<b>Quadriplegia</b>	Also known as tetraplegia; paralysis affecting all four limbs.
<b>Range of motion</b>	Normal movement of a joint, typically restricted by injury.
<b>Reflux</b>	Back flow of a liquid against its normal direction.
<b>Regeneration</b>	The re- growth and reconnection of damaged nerves. The process of repair occurs naturally in the peripheral nervous system, but not in the central nervous system (brain or spinal cord). Functional regeneration remains a very difficult problem.

Word	Explanation
<b>Rehabilitation</b>	A set of services to restore maximum function; physical, psychological, vocational and social – to a person with a disability.
<b>Reciprocating Gait Orthosis (RGO)</b>	This is a leg and waist brace system that allows paraplegics to stand and to swing their legs in a gait pattern; require less energy than other types of braces.
<b>Rhizotomy</b>	The cutting of nerves to interrupt spasticity or pain signals.
<b>Secondary conditions</b>	A primary condition is a medical diagnosis: spina bifida, spinal cord injury, etc. A secondary condition is any medical, social, emotional, mental, family or community problem that a person with a primary condition may experience, such as pressure sores, pain, depression, reduced social life, lack of gainful work, etc.
<b>Secondary injury</b>	A cascade of chemical activities following trauma to the brain or spinal cord that contribute to the damage. Included is swelling, loss of blood flow, release of free radicals, excitotoxic amino acid release.
<b>Sialorrhea</b>	The term for excessive salivation and drooling.
<b>Shear</b>	The friction on tissues caused by dragging across a surface can cause skin to break down.

Word	Explanation
<b>Spasticity</b>	Uncontrolled muscle activity. This condition can be beneficial for muscle tone but can interfere with every day activities.
<b>Sphincterotomy</b>	A surgical procedure to relax the urethral sphincter, thus improving bladder function. An alternative is the placement of a stent, which is reversible. Botulinium toxin (Botox A) has also been used to relax the sphincter.
<b>Spina bifida</b>	Congenital spinal cord dysfunction due to malformed neural tube during prenatal development.
<b>Spinal shock</b>	After the initial spinal trauma, this condition, similar to a coma from a brain concussion occurs; the nervous system shuts down and the body become flaccid. Can last for three or four weeks.
<b>Stoma</b>	(Greek word meaning mouth) A surgically created opening from the skin to the deep viscera (internal organs) for the purpose of collecting the contents.
<b>Stroke</b>	A 'brain attack' (Cerebrovascular accident – CVA) leading to the loss of brain tissue' caused by bursting (haemorrhagic) or blocked (ischemic) blood vessels in the brain.
<b>Suprapubic cystoscopy</b>	An opening through the abdomen to drain the bladder with a catheter, known as a 'super tube'.

Word	Explanation
<b>Sympathetic nervous system</b>	A subset of the autonomic (involuntary) nervous system that accelerates heart rate, constricts blood vessels and boosts blood pressure.
<b>Syringomyelia</b>	A disorder caused by formation of a fluid-filled cavity (syrinx) within the spinal cord.
<b>Syrinx</b>	A cavity in the spinal cord that fills with fluid.
<b>Tendon transfer</b>	A type of hand surgery that offers certain quadriplegics significant increase in hand function. Takes advantage of functioning muscles in the arms by moving the tendons that control the hands.
<b>Tenodesis</b>	This involves stabilizing a joint by anchoring the tendons that move the joint.
<b>Tetraplegia</b>	Paralysis affecting all four limbs. Also known as quadriplegia.
<b>Thoracic</b>	The portion of the spinal column in the chest, between the cervical and thoracic areas.
<b>Thrombosis</b>	The medical term for a blood clot.
<b>Tracheostomy</b>	An opening in the neck at the front of the windpipe to help breathing.
<b>Transverse myelitis</b>	Inflammation in the spinal cord interfering with nerve function below the level of the inflammation. An acute attack of inflammatory demyelination.

Word	Explanation
<b>Upper Motor Neurons</b>	These are the long nerve cells that originate in the brain and travel through the spinal cord. Disruption of these cells leads to paralysis, although some reflex is still possible.
<b>Ureter</b>	The canal that conducts urine from the kidney to the bladder.
<b>Urethra</b>	The canal that leaves the bladder and ends outside the body which urine passes through to be excreted.
<b>Urinary calculus</b>	Solidification of mineral salts in the urine. A stone can block the kidney, the ureters or a catheter and its elimination through the natural pathways may irritate the bladder and cause bleeding of the bladder lining. Calculi are caused by urinary infections, an overly strong concentration of urine due to low fluid intake and the use of indwelling (permanent) catheters. Urinary infection has a tendency to make the urine alkaline, which leads to a precipitation of the calcium contained in the urine. Infection and urinary calculi almost always go hand in hand.
<b>Urinary Stenosis</b>	Pathological shrinking of a urinary orifice or canal.
<b>Vertebrae</b>	Each of the bones that form the spinal column.
<b>Vesico-Spinal</b>	Relating to the urinary bladder and spinal cord.

<b>Word</b>	<b>Explanation</b>
<b>Vital capacity</b>	The maximum volume of air that can be expelled from the lungs on forced expiration, following maximum inspiration. It is measured using a spirometer.
<b>Warfarin</b>	A commonly used anticoagulant, also known as Coumarin.
<b>Weaning</b>	The gradual removal of mechanical ventilation as a person's lungs gain strength.
<b>White Matter</b>	The outer portion of the spinal cord containing nerve tracts that are covered by myelin.

We would like to thank the staff, Spinal Injuries Scotland, patients, families and volunteers for their contribution to this booklet.