

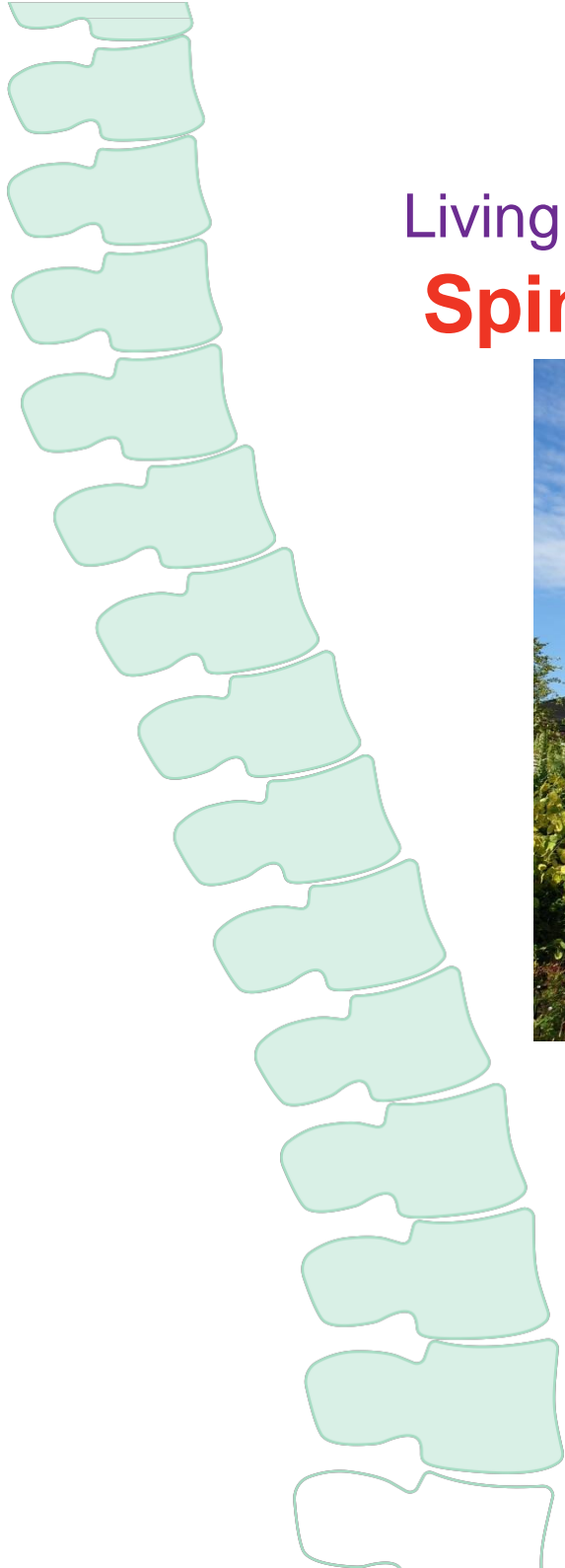
Living with a  
**Spinal Cord Injury**



[The Duke of Cornwall Spinal Treatment Centre](#)  
**Salisbury District Hospital**  
**Odstock Road**  
**Salisbury**  
**Wiltshire**  
**SP28BJ**  
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Information after a

**Spinal Cord Injury**



# Contents

## Section 1

- Personal Information 1. 1
- Contact Telephone Numbers 1. 2
- Introduction to the Duke of Cornwall Spinal Treatment Centre 1. 4
- Partnership Working 1. 9
- Our Agreement 1. 10
- Your Treatment Plan 1. 11
- Expected Behaviour 1. 12
- The Anatomy of Spinal Cord Injury (SCI) 1. 13
- Psychological Adjustment after a Spinal Cord Injury 1. 19
- Personal Stories 1. 22
- Spinal Charities 1. 37
- Spinal Injuries Unit Floor Plan 1. 42
- Horatio's Garden 1. 43

## Section 2

- Respiratory Complications after Spinal Cord Injury 2. 1
- Skin Care after your Spinal Cord Injury 2. 9
- Managing your bladder 2. 21
- Managing your Bowels 2. 34
- Sexuality after your Spinal Cord Injury 2. 51

## Section 3

- Staying Fit and Well After Spinal Cord Injury 3. 1
- Autonomic Dysreflexia 3. 8
- Muscle Spasm 3. 11

- Neurogenic Pain 3. 13
- Upper Limb or Hands Splints 3. 14
- Foot care Advice 3. 16
- Temperature Control 3. 18
- Functional Electrical Stimulation 3. 19

## Section 4

- Discharge Planning 4. 1
- Housing 4. 3
- Education and Employment 4. 5
- Wheelchair Maintenance 4. 9
- Spinal Outpatient Clinic 4. 11
- Short Stay Assessment 4. 19

## Section 5


- Information about Driving 5. 2
- Transport 5. 10

## Section 6

- Operations, Appointments and Tests 6. 2
- Equipment list 6. 3
- My Notes 6. 4
- Glossary 6. 5



## Section 1

- Personal Information . . . . . 1. 1
  - Contact Telephone Numbers . . . . . 1. 2
  - Introduction to the Duke of Cornwall Spinal Treatment Centre . . . . . 1. 4
  - Partnership Working . . . . . 1. 9
  - Our Agreement . . . . . 1. 10
  - Your Treatment Plan . . . . . 1. 11
  - Expect Behaviour . . . . . 1. 12
  - The Anatomy of Spinal Cord Injury (SCI) . . . . . 1. 13
  - Psychological Adjustment after a Spinal Cord Injury . . . . . 1. 19
  - Personal Stories . . . . . 1. 21
  - Spinal Charities . . . . . 1. 37
  - Spinal Injuries Unit Floor Plan . . . . . 1. 42
  - Horatio's Garden . . . . . 1. 43
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## Personal Information

Name:	
Level of injury:	
Cause of injury:	
Medical History:	
Allergies:	

## Contact Telephone Numbers

### Hospital Team

Your Consultant is: \_\_\_\_\_

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

	Telephone Number:
<b>Longford Ward</b>	01722 336262 Ext 2447
<b>Lead Nurse</b>	01722 336262 Ext 4267
<b>Specialty Manager</b>	01722 336262 Ext 4267
<b>Resource Co-ordinator</b>	01722 336262 Ext 2144
<b>Spinal Outpatient Department</b>	
Outpatient Occupational Therapist	01722 336262 Ext 4339
Outpatient Physiotherapist	01722 336262 Ext 4339
Outpatient Nursing Team	01722 336262 Ext 4291
Outpatient Clinical Nurse Specialist	01722 336262 Ext 4130
<b>Outpatient Appointments</b>	01722 336262 Ext 4084
<b>Respiratory Clinical Specialist</b>	01722 336262 Ext 2084
<b>Spinal Inpatient Department</b>	
Inpatient Physiotherapy Team	01722 336262 Ext 2455
Inpatient Therapy Clinical Specialist	01722 336262 Ext 2454
Inpatient Occupational Therapy Team	01722 336262 Ext 2071
Therapy Team Leader	01722 336262 Ext 2454
<b>Clinical Psychologist</b>	01722 336262 Ext 4111
<b>Education Lead Nurse</b>	01722 336262 Ext.2084
<b>Discharge Co-ordinators</b>	01722 336262 Ext 5659
<b>Recreational Assistants</b>	01722 336262 Ext 2108

## Community team

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

## Introduction to the Duke of Cornwall Spinal Treatment Centre

In order for you to make the most of your time here, and make as much progress as possible, we will work with you to develop your own personal treatment plan. As individuals we all have hopes and aspirations and only by forming a partnership with the Centre staff can these be recognised, understood and incorporated into your rehabilitation plan.

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 familiarize 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 one ward: Longford Ward as well as an Outpatient department.

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.



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 Longford depends on medical factors and whether you are ready for rehabilitation.

### Medical Staff

The Spinal Centre has 3 Spinal Cord Injury Consultants:

- Mr Bandi
- Dr Fard
- Dr Vinod

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

The centre also has a range of other doctors and specialists.

## Ward Rounds

While on Longford ward, you will see the doctors once a week during ward round. This happens on a Monday or Thursday in the morning. Our ward rounds are attended by the [Multidisciplinary Team](#). This can include the Doctors, Nurses, Physiotherapists, Occupational Therapists, Psychologist and the Discharge Coordinator. This means that a large team will be seeing you by your bed. We appreciate it might be overwhelming seeing so many people at once. But this is an occasion for the whole team to get together with you and make plans according to your needs.

The main aim of the ward round is to monitor your health, make sure you are making progress with your rehab setting new goals and make plans for your discharge. You can discuss any concerns with the doctors during the ward rounds or you can arrange a separate time to meet with your consultant.

## Longford and Rehabilitation

Rehabilitation is a process that you go through to maximise your potential. Rehabilitation is not just Physiotherapy or Occupational therapy. Each component is equally important and includes ALL of the Multidisciplinary team. The nursing input is very much part of your rehabilitation. They will explain to you why you require the care that you do. Our aim is to make you well informed about how your spinal cord injury affects you.

Psychological support is equally important and can help prepare you for your discharge and adjustment to your spinal cord injury.

On average, patients are in the Spinal Centre for 12 weeks. However, this may vary from 1 month to 9 months depending on your circumstances.

The Multidisciplinary team will regularly review your progress with you and set new goals. Your family are welcome to be involved with these discussions as we recognise their importance in your rehabilitation too.

This holistic, individual approach is important so that you (and your family) have the knowledge to be able to direct others about your own

spinal cord injury and how it affects you.

### Rehabilitation Staff

During your rehabilitation, much time will be spent working with the nurses, physiotherapist, occupational therapists and psychologist as you gradually meet your goals and objectives. The Doctors will oversee your medical care. At this stage you will be encouraged to do as much as you can for yourself. The staff will continue to help you with the things you cannot do. For you to be able to direct your own care needs is very important and will help to make the transition from hospital to home as smooth as possible. It is the norm to meet with the Clinical Psychologist. Our Psychologist is an integral part of your rehabilitation team. As well as focusing on your physical recovery, it is important to acknowledge how you feel emotionally. Having a spinal cord injury can be a life changing and a massive adjustment. We recognise the importance in how to assist you in how you manage that.

The Spinal Centre is a rehabilitation centre that encourages patients to lead a more independent life following injury. As part of the rehabilitation process we encourage all patients to keep their family/loved ones updated with their progress during their stay. Staff do not routinely contact family or loved ones unless they are asked by a patient. If you do not have the means by which to contact your family or loved ones, please ensure that you speak to the nurse in charge in order that we can facilitate this for you.

Any questions



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

## Partnership Working

### **PARTNERSHIP WORKING**

Salisbury Regional Spinal Treatment Centre promotes a process of rehabilitation that actively encourages people to take control of their lives following their spinal cord injury.

We will endeavour to ensure that everyone who receives care, visits or works within the Centre should not be subject to unacceptable behaviour by others.

## Our Agreement

### **OUR AGREEMENT**

We fully respect your rights and those of your family to receive appropriate and compassionate care.

We will guarantee care is provided in a clean, safe environment.

We promise that all staff caring for you has the appropriate knowledge and training to ensure you receive evidence-based specialist care.

We will ensure all staff adheres to infection control guidelines

We will deliver care in a friendly yet professional manner.

We will ensure that we maintain an open and honest approach and clearly communicate your treatment plan with you.

We promise to ensure you have the necessary information to make informed decisions about your treatment plan and we will respect those decisions.

We will comply with the agreed treatment plan.

We will regularly review your estimated discharge date and ensure it is realistic and achievable.

We will provide opportunities for you and your family to discuss any concerns or issues with your Consultant or Matron at your request.

We will respect your right to privacy and confidentiality regarding your care and treatment.

We will endeavour to ensure that everyone who receives care, visits or works within the Centre should not be subject to unacceptable behaviour by others.

### **YOUR TREATMENT PLAN**

In addition to rights, you also have responsibilities both in applying yourself fully to the entire rehabilitation process and respecting the needs of other patients, staff and others within the Centre. We aim to provide an environment without too many rules but would ask you to show respect and consideration for others.

You promise to be open and honest in sharing information that may impact on your treatment plan.

You agree to comply with the agreed treatment plan.

You understand that you will be expected to attend and actively engage in all scheduled therapy sessions unless otherwise agreed arrangements are made.

You agree to refrain from taking food other than fluids into the therapy areas

You agree that until deemed safe by your treating team you will not leave the Centre without an escort.

When leave is authorised, you will inform the nurse in charge on leaving and return to the Centre.

You agree and understand that it may not always be possible for you to be discharged directly to your own home on completion of your rehabilitation. You will therefore actively engage in the discharge process and identification of a safe placement to avoid a delay in your agreed discharge date.

## Expected Behaviour

### **EXPECTED BEHAVIOUR**

You will not wilfully damage Trust property or that of others.

You agree to respect staff and other patients in relation to noise, loud TV, music or conversation particularly at unsocial times.

You will ensure use of mobile phones is respectful towards others. You will switch off your phone during treatments or therapy sessions.

You promise to respect staff, other patients and visitors by appropriate dress, language and behaviour acceptable to mixed social groups.

You will not use aggressive behaviour, both verbal and physical, towards staff, other patients and visitors within the Centre.

You will refrain from the misuse of any alcohol or illegal substances.

You will not smoke within the hospital grounds. The whole hospital has a no smoking policy. Vaping is allowed in designated areas.

### **BREACH OF THE PARTNERSHIP WORKING DOCUMENT**

As a patient of the Spinal Injuries Centre you agree to comply with the above. If you believe there may be a problem adhering to anything contained within this document, please discuss with your consultant.

Please do not hesitate to bring to the attention of your Consultant or Senior Nurses any non-compliance of the above agreements by the Trust. This will then be fully investigated in line with relevant Trust policy.

If there is any breach of the agreement by you we will follow the guidelines set out in the relevant Trust policies

If breaches continue and Partnership working is deemed irreconcilable by the Trust or you it may be necessary to commence arrangements to arrange transfer to another care provider or expedite discharge from the Centre



# 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

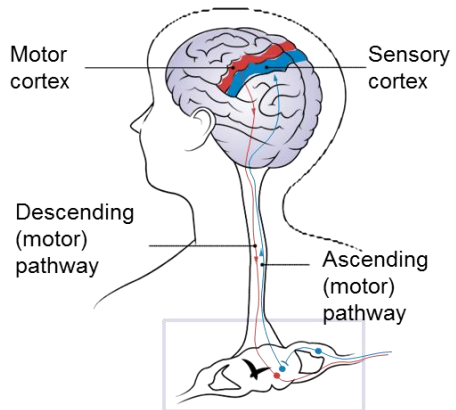
This carries information from the brain downwards to initiate movement and control body functions. This is coloured red in the diagram. Any damage to the motor nerve pathways, within the spinal cord, will result in the brain not being able to initiate movement and control within the body below the damaged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

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.

**Major Nerve Pathways of the Spinal Cord**



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

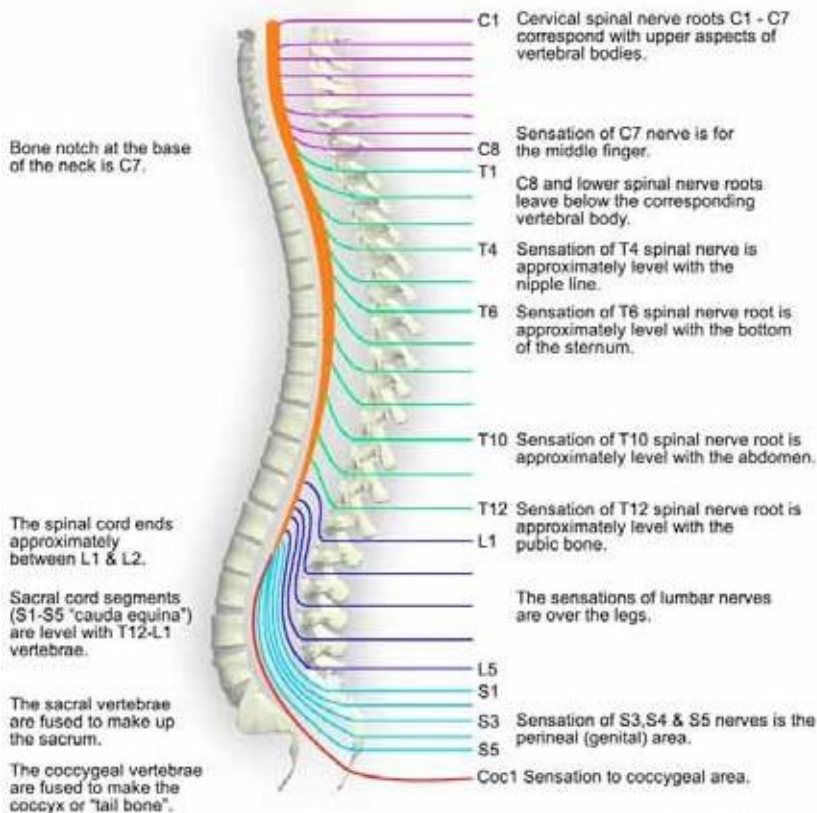
**Lumbar** 5 vertebrae and 5 pairs of nerves that serve the upper and anterior (front) sections of the legs

**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.

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 fractures 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 within 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 and hands. These individuals sometimes recover enough to walk a little but may continue to have major problems with their arm and hand 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 parts 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 11<sup>th</sup> and/or 12<sup>th</sup> Thoracic 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

## 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 Longford, 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. Some people find it is helpful to understand their injury in detail early on 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 want. If and when you feel ready, you can ask for a meeting with your consultant to view your scans and discuss your injury in more detail. You can include your family in this if you want to.

### 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

You will have been transferred from an 'acute ward' in your previous hospital, to Longford Ward. Longford Ward is a 'rehabilitation ward'.

The aim of rehabilitation is to help you to learn about your injury, how to manage the issues associated with it, & to work towards maximising your potential. On a 'rehabilitation ward' you are actively encouraged to participate in your care, do some of it independently if you can, or learn how to direct others in how to care for you if can't.

For some people, the change from an 'acute ward' can leave them feeling uncertain to start with. Staff understands that the transition can be stressful. They are here to support you and answer any questions you may have.

After possibly spending weeks or months lying down on a bed, 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 usual. The Clinical Psychologist on Longford Ward is used to meeting all sorts of people- from those who have had never needed psychology services before, to those with a history of emotional challenges.

Seeing the psychologist can be a positive part of your multidisciplinary rehabilitation. If a member of staff feels that you would benefit from seeing a Clinical Psychologist, then they will discuss this with you. You can also request an appointment yourself. An appointment will only be made if that is what you want; but many people find it very helpful to talk through their situation. The psychologist will ask you about your feelings and concerns. They will ask how you are coping, and encourage you to explore ways of moving forwards.

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 and the psychologist see as being helpful. You may also be directed to group support where you can benefit from the shared experience and support of others.

### Long Term Outcome

How someone copes in the longer term does not depend on their level 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.

## Personal Stories

### *Helen*

I was then 19 years old, a teenager looking forward to a career in the Police force or to train as a nurse.

Unfortunately, one evening on route home and as a passenger in a car I would not return home for 10 months. After spending a month in a ventilator in Cheltenham I was then transferred to the intensive care unit at Odstock hospital. When I eventually awoke one of my first memories was a windswept gentleman introducing himself as a spinal consultant! He informed me that I would later be transferred to the spinal unit. I didn't really understand what that really was or what was to come.

I spent a further 6 weeks on a ventilator and then one afternoon was dressed and sat up in a wheelchair, I remember thinking "this is a lot of effort for a few minutes sitting up", but only when in the chair I felt like a rag doll and could not wait to get back into bed as my head was spinning and I felt very sick.

I'm not going to ramble on about the months that followed, all I will say is that I formed some wonderful friendships and 26 years later I'm happy to share all the positives of my life.

After leaving hospital as a teenager I enrolled on a computer programming course to ensure I could support myself. I hated it but knew I had to adapt to learning new skills to fund my new chapter. I moved into a little bungalow, which looking back now was a positive because on a night out with friends I met my now husband.

We "dated", does that sound old fashioned?? Well, we did, and I often thought "what does this handsome young man see in me, I'm paralysed". My mum would always say "you are still you".

Well, a few years later the young handsome man and I married. We bought our own home and have the gift of a daughter.

I remember the spinal consultant telling me all those years earlier that there would be no reason I couldn't have a baby and he was right the only thing that had stopped me was my head! My daughter has been a blessing and I can't tell you how much she has enhanced my life.

Throughout all the positives there have been a few life changing sadness's, loss and bereavement but those things would have happened spinal injury or no spinal injury.

I hope from reading a small insight into my life that this will provide you with the hope to live your life to the full. Yes life is different, but actually as a young lady I have all those things I ever dreamt of. I knew I wanted to have a job that I enjoyed, meet a like-minded man to marry, own my own home and actually I've ticked all the boxes. I'm really proud of who and what I have become, through sheer determination, a sprinkle of perseverance I'm doing ok.

Be strong, be proud, be resilient and make every day count, be you.

Now go live, you can do this

### *Stephen*

I sustained my injury in 1998 at T6 complete following a motorcycle RTC. At that time I was a serving police officer but following my injury was medically retired from the police force. I felt a little lost for a while but returned to college to study and work in sports science and coaching before going to university to train as an occupational therapist (OT). I have been an OT for 12 years now and absolutely love being able to use my professional skills and personal experience to help others. I have also been very lucky to have three beautiful children since my injury and enjoy being an active dad. My injury has never held me back and I have always remained positive about the course my life has taken.

### *Sean*

I broke my neck in a snowboarding accident in April 2000. I spent 9½ months at the spinal centre in Salisbury before returning to live in London. I got involved with the charity [Back Up](#) who showed me what was still possible - I did things like kayaking, hand cycling and even got back on the slopes skiing with them and I haven't looked back since. It was great to meet others with SCI who were further down the line and getting on with life. I now work for Back Up as Head of Fundraising and more recently I got married and have two wonderful daughters. I still manage to get out on my hand bike, though sadly the skiing trips are less frequent now! It all feels a long way from those early days after my injury when I thought life was pretty much over - it's been a rollercoaster, but I've had some amazing experiences and life over the past 20 years has been good.

## *Giles*

I was in the Spinal Unit 2002 and wished I had died after my accident, but 18 years on I'm married (in 2009) to my beautiful wife Ania for the past 11 years and I'm happy as a pig in s###! As long as you're alive you're winning.

## *Roy*

I had fall in 1992 which resulted in a C6 complete injury. Initially, it was difficult after I was discharged, and I had some challenging times. I did get through it with support and I got married and now have two beautiful children.

I enjoy hand cycling, cinema, gardening and watching sport. I work and still enjoy life at 51yrs old. I work for a spinal charity called [Aspire](#) as an [Independent Living Adviser](#). Having a spinal cord injury, myself means I can relate directly to what patients are going through, and am on hand to share my knowledge and experiences with any patient who needs to talk.

## *Phil*

A spinal cord injury doesn't stop life unless you let it – embrace it, live it!

## *Anthony*

Whilst I was in the spinal unit, I was unsure what life would be like back in Jersey, we had to move from our bungalow, which was not suitable for a wheelchair, to a ground floor apartment, which has worked out well.

I also thought I would never be able to visit our apartment in Portugal, which was on the second floor. During my stay in Salisbury, my wife visited Portugal a couple of times and had the en-suite altered into a wet-room so I could enter in a shower chair and arranged for a hospital type bed with air mattress and a Voyager hoist to be installed to get me in and out of bed.

Flying with British Airways is not a problem; even though we have to change planes at Gatwick I have assistance throughout. They use the lift to get me to the side of the plane and lift me into a small chair, which fits down the aisle to take me to my seat.

Whilst in Portugal the local government office ran a photographic competition, where they required 3 photographs showing good access for wheelchairs and 3 with bad access, I enclosed a copy of me outside our apartment block, showing bad access, as they had cut off the end of the ramp once the block was finished as it encroached on the pavement. (I have to go in and out through the garage and use the lift).

To my amazement it won 3rd prize!



## *Christine*

“In a weird way if it were not for becoming paraplegic, I might have had an extremely boring, run-of-the-mill life”.

Following the partial removal of a spinal tumour I was fortunate to receive fantastic rehabilitation as a patient of the Spinal Centre. I was soon able to return to my work as an Occupational Therapist (O.T.) in Adult Mental Health in Havant, Hants.

In 1987 I took up the opportunity to learn to ‘sit-ski’ with the help of BACKUP and Solent Ski Club for the Disabled, becoming its ‘Chair’ in 1998.

In 1990 I became the first woman to represent G.B. in the World Cup Ski Championships in Winter Park, Colorado, where I double medalled in the Women’s Downhill and Combined events. I went on to ski in the 1992 Winter Paralympics, Albertville, France.

To compliment my skiing, I took up wheelchair tennis in 1990. With much support from The British Tennis Foundation I represented G.B. in several world events including the Summer Paralympics in Barcelona 1992, becoming the only British woman to compete in 2 Paralympics in the same year.

Retired from competitive sport, I now enjoy tending and relaxing in our beautiful garden with my husband. We have made it a haven for wild birds and spend many springtime hours watching them in their nests using ‘nestcams’.

I was victim of a serious car accident in 2001, causing me some significant challenges, so I reduced my working hours to have a better work life balance.

Now I was able to spend more time on my hobbies. I rekindled my mothballed hobby of restoring old dolls houses and amazingly found a local club of like-minded hobbyists who welcomed me as a member.

I joined Rock Choir in 2009, now Britain’s largest contemporary choir, singing Rock, Pop, Gospel, and Motown and I love it. It is

a great workout out for ‘mind, body and soul’. I have sung in some amazing places. Abbey Road, International Rugby matches,

Wembley, The O2, and twice at 'Proms in the Park', amongst many.

In 2012 I decided to fully retire, having a bit of a leaving bash by coincidence on the night the Olympic Games opened in London!

Two weeks following my last day at work and quite unplanned, we were owners of a beach hut at Calshot. It has a small cooker; we are often there for a bacon butty breakfast or on a summers evening for a fish and chip supper on the beach watching the sun set. Even in the winter it's our great escape.

With a friend I still make quality bespoke greetings cards, which we sell privately and at a few craft fairs, generating enough money to replenish our stock and donate the remainder to different Charities. Orders always welcome!

This includes a group for folk experiencing chronic pain, for whatever reason, called Keeping Pace With Pain. A support group in Southampton, I feel lucky that there is such a group locally, as there are very few of these across the country. We all have a common bond and understanding. If one of us is having a bad pain day, no questions asked, but care and support aplenty, if needed. So.....not a load of 'wingers', but a vibrant bunch, getting on with life.

In 2015 I was lucky enough to join a second choir, singing with The Bournemouth Symphony Orchestra. Nothing quite prepared me for the incredible and unbelievable experience of singing with one of the largest and most recognised provincial orchestras in Great Britain! What a sound. I still find every concert spine tingling! Yes, it can still tingle!

In 2018, having not picked up a tennis racquet for over 16 years, I was invited to take part in The Dan Maskel Reunion Tennis Tournament. Panic!!!! Not wanting to embarrass myself, I quickly organised a few on court practice sessions. What a joy it was to meet up with some friends from the past and some newcomers to the game. We have a whole weekend of relaxed and sometimes hilarious tennis. This has now become an annual and 'must go to' event in my calendar.

So, life is great, every day is mine to do as I wish, well almost..... So, bring it on!!!!!!!

What a world has been opened up to us!

### *James*

At the young age of 16 I was air lifted to the spinal unit, miles away from my home in Devon. I had noticed that everyone around me was in a wheelchair and I wondered if that was my fate too. The Doctor nodded; I had broken my T12 and L1 vertebrae. I spent a total of eight months in Salisbury, 110 miles from my family and home in Kings Nympton and can honestly say that I went into hospital a boy and came out a man.

After 6 weeks of being on bed rest not being able to do anything I was allowed to start getting into a wheelchair. This felt very strange as it all became real that I would be spending the rest of my life in one!!! Every day I could see improvements in strength by going to the gym and working with the physios. There was so much to take in from all the nurses and consultants, from looking after your skin, making sure that I was drinking enough water and trying to keep in the best of health. At my age I did not take on the importance of what everyone was telling me. It felt a bit like being back at school (which I didn't enjoy). The Spinal Unit is a safe, accessible place with staff there to help you any time you need it. After leaving the unit after 8 months I soon realised I was on my own and wished I had worked harder doing my exercises and also listening to the experts. I didn't grasp the benefits of some of the things I was encouraged to do.

The real world is very different and not always as accessible. They were all trying their best to help me and all I wanted to do was get home and start going out with my mates again! Hindsight is a wonderful thing!

After leaving the Spinal unit I had no idea how I was going to fill my days.

For quite a while I did absolutely nothing! I had always been quite sporty; I enjoyed cross country running and played both rugby and football.

I got into a bad routine of going to bed late and getting up very late!!! After a while, I thought I really need to get back to work. I managed to secure a part time job working for Adaptacar. My role in the company is advising customers on what adaptations are on the market. It can be very

rewarding seeing customers that thought they would never drive again get behind the wheel!!

I had more than a passing interest in motor sport and rallying in particular. After watching events again and taking in the atmosphere, the smells, the roar of the engines, I knew I wanted to try and take part and compete myself. It wasn't an easy journey, but I was determined and achieved my licence to race.

I have taken part in the British Rally Championship Challenge. I have competed in both forest and tarmac events, with some very good results, winning 1st class on several occasions, but I have also had some spectacular mishaps. I would urge anybody interested in the sport to give it a try, its brilliant fun. You meet great people, have the chance to travel around the country and there is no better feeling than beating our able-bodied counterparts!

Before my accident I worked on a farm. It has always been in my blood. I started helping out on a friend's sheep farm. I brought a quad bike to help me get across the land. I soon found out pushing a chair over rough ground wasn't easy!! While I was out checking some sheep, I noticed another farmer carry out a job with his tractor. I thought to myself. I do miss that bit of farming. So, I looked into buying a tractor, I found a second-hand tractor that I could drive. With some very good friends of mine we designed a lift to get me from my wheelchair up into the cab. Once a few farmers knew I had a tractor the phone started to ring. As I hadn't driven a tractor for about 18 years it was all exciting and I couldn't wait to get going.

This inspired me to buy my own land and with my partner Angela we keep sheep and some pigs. It is hard work and long hours, but it is a brilliant lifestyle.

*Simon*

Simon from Somerset and his fundraising dogs Fudge, Miele and Olga have raised in excess of £55,000 over a period of eleven years in aid of the charity [Support Dogs](#) from Sheffield.

This is a great achievement by any body's standards, but back in 1999, Simon had to overcome one of the biggest challenges he would ever face. Aged just 42, Simon had a near fatal accident at

work whilst riding his Police patrol motorcycle. The accident left him paralysed from the waist down and he spent 15 months at Salisbury Spinal Unit.

Unlike most, Simon was determined that his injuries would not beat him. He said: "I felt so humbled by the whole experience, the fantastic care and help I received during this time, I felt in my heart that someday, somehow I wanted to give something back in return."

Simon and his German shorthaired pointers have supported the charity since 2004. Simon came across the

Support Dogs website, where he applied to be a guest speaker/fundraiser for them, and he hasn't looked back since!

Despite his accident on his motorcycle he remains a keen motorcyclist but now on three wheels.

### *Hela*

I want to share my story as it might give hope to other patients with spinal cord injuries and to thank the staff at Salisbury District Hospital who worked so hard to make life better for me.

It has been a journey; I struggle with the pain and depression related to that. I now practice mindfulness which helps. I have found that instead of comparing what I can and I can't do to my pre-injury self I can now move on and accept my new life. I constantly challenge myself in different ways. I learnt to bake, I potter in the garden and volunteer in the community.

There is always hope, you just have to take one day at a time. You are stronger than you think. Be kind to yourself.

*Mike*

I have a C6/7 tetraplegia, but I am lucky enough to have completed 158 marathons in a racing wheelchair. These have taken place in Egypt, Dubai and Jamaica but mainly in Europe and the USA. I am especially proud of the fact that I have come LAST in every one of them. Yes – I am a truly, lousy wheelchair racer, but I love it so who cares!

I travelled to those marathons on my own which made each trip a slightly scary adventure. What made that possible was a tendon transfer in the lower part of my left arm. That gave my left hand an extremely basic, functional grip which, until the transfer, had been completely useless. It'll never be good enough to enable me to play the piano but I never could anyway so, no drama. Sure enough it's great for helping me get ANOTHER bottle of wine out of the fridge (doesn't help the hangover though) and for picking stuff off the shelves in the supermarket (shopping..ugh). But the life changing aspect of the tendon transfer was that it allowed at least one hand to grip the push-rim of my day chair – and THAT gave me a degree of control that I hadn't had until then – and that in turn meant I could travel alone. Yippee.

I completed a PADI diving course which meant I could go diving out in Egypt with a group of disabled ex-service men and women. Some of the drills required were a challenge. With the wonderfully functional hands (NOT) us quads are left with, having to remove and replace your face mask and demand valve underwater is a task that does give cause for a touch of careful consideration, even with my beloved tendon transfer.

I have also done three sky dives, which involves being strapped to the chest of a very experienced skydiver and then rolling out of an aeroplane between 10 to 12 thousand feet above ground. I can honestly say my entire contribution was to clamp my eyes closed and send non-stop prayers to whoever may have been listening.

And lastly but by no means least, I have been skiing numerous times with Back-up. The Tetras get to use ski karts (like go-karts but with skis not wheels - very stable) whereas the paras have to learn on the very unstable sit-skis. Which is brilliant because they spend days falling over and eating snow while we are off down the slopes having fun? Highly recommended.

## *Amie*

After being involved in a car accident in April 1997 at the age of 16, I was left with a T10 spinal cord injury. Spending 3 months of bed rest and then a further 5 months being rehabilitated, seemed an eternity, but looking back now I know if it wasn't for the hard work and dedicated staff, I would not be who I am today. After leaving my "second home" (The Spinal Unit) just before Christmas 1997, I returned home with my parents and settled back to normality. I then returned back to school and finished off the course I was taking before I had my accident, I then went on to college. There I met new friends and most importantly was introduced to my future husband. I got married and thanks to Odstock Medical Physics team I was able to walk down the aisle on my dad's arm, which I never thought would happen. After returning back from honeymoon I had an invite to join the workforce at the college where I had been a student, so for 2 years I was teaching information technology to 16-18 year olds. I found this time very useful as not only was I teaching IT, but able to help others understand about people with spinal disabilities. If they had questions, I was happy to answer them, no matter how weird! After 2 years I left to start my family, and in July 2004 I gave birth to my first son and then in October 2006 I gave birth to my second son. They keep me extremely busy and I find everyday a great challenge, but I wouldn't change anything! When lying on the hospital bed looking up at the square tiles on the ceiling, I would never have imagined I could be as happy and content as I am now. Yes, I still have bad days and I get frustrated when I cannot do something, but when I think of the things I have achieved since my accident, the little things I cannot do don't matter!



## Spinal Charities



At [Back Up](#), we inspire people affected by spinal cord injury to get the most out of life.

For over 30 years, we've helped people and their families to rebuild their independence after a devastating spinal cord injury. Our award-winning, practical services challenge the perceptions of what's possible and increase your skills and confidence. Back Up offers a variety of [courses](#) to help build confidence and your own independence.

Today, we're at the forefront of helping people adjust positively to spinal cord injury because our support is provided by people who have been there and can understand what you are going through. At Back Up, we're here for people in their darkest hours so they get back up to living life to the full.

Back Up's [mentoring](#) service, accredited by the [Mentoring and Befriending Foundation](#), links people with a spinal cord injury and their family members to volunteer mentors. These mentors come from all walks of life and have been through a similar experience to their mentees. They understand and can help you come to terms with what has happened and adjust to life post-injury.



The [Spinal Injuries Association](#) (SIA) is a leading UK charity which provides invaluable support to people who have suffered a spinal cord injury. The charity's support starts from the moment someone becomes paralysed and continues throughout their lifetime.

The SIA has an advice line which provides information to individuals, relatives and friends to help them understand more about spinal cord injury. The [advice line](#) provides support and practical information on a range of topics that people with a spinal cord injury encounter on a day-to-day basis, such as housing, returning to work, funding and holidays.

It has often been said that the best support for spinal cord injured people comes from their [peers](#). If you have received treatment in a spinal cord injury unit, you will have probably had support from other people with similar injuries who are also undergoing rehabilitation. You will also probably want to know what life is like a year, or more, down the line.

SIA offer a free, confidential [telephone counselling](#) service to you, your family and friends.

There is a wealth of up to date [information](#) relating to all aspects of living with a Spinal Cord Injury. SIA run [education days](#) which are led by their [Clinical Nurse Specialists](#).

# Aspire

Supporting people with spinal injury

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[Aspire](#) provides practical help to people who have been paralysed by Spinal Cord Injury, supporting them from injury to independence.

Our [Independent Living Advisors](#) provide advice and guidance to patients in Spinal Injury Centres.

Aspire can also offer support for [Housing](#), [Welfare Benefits](#), [Grants](#) and [Assistive Technology](#)



[Regain](#) has been established to help people who have had a sports related *spinal* cord injury resulting in tetraplegia/quadriplegia. [Money](#) is available for potential REGAINERS to help provide them with the specialist equipment they need to enable them to achieve greater independence and improve their quality of life.

Through our [Transforming Lives Campaign](#), we're delighted to hold Information Days to Tetraplegics across the UK.



[Southern Spinal Injuries Trust](#) (SSIT) raises money to help people living with spinal cord injury in the South and South West of England and to support The Duke of Cornwall Spinal Treatment Centre.

**Our goal is simple: to assist people with spinal cord injury, enabling independence and quality of life.** This can mean anything from funding resources for the spinal centre to [funding individual](#) needs in respect of specialist equipment or other assistance.

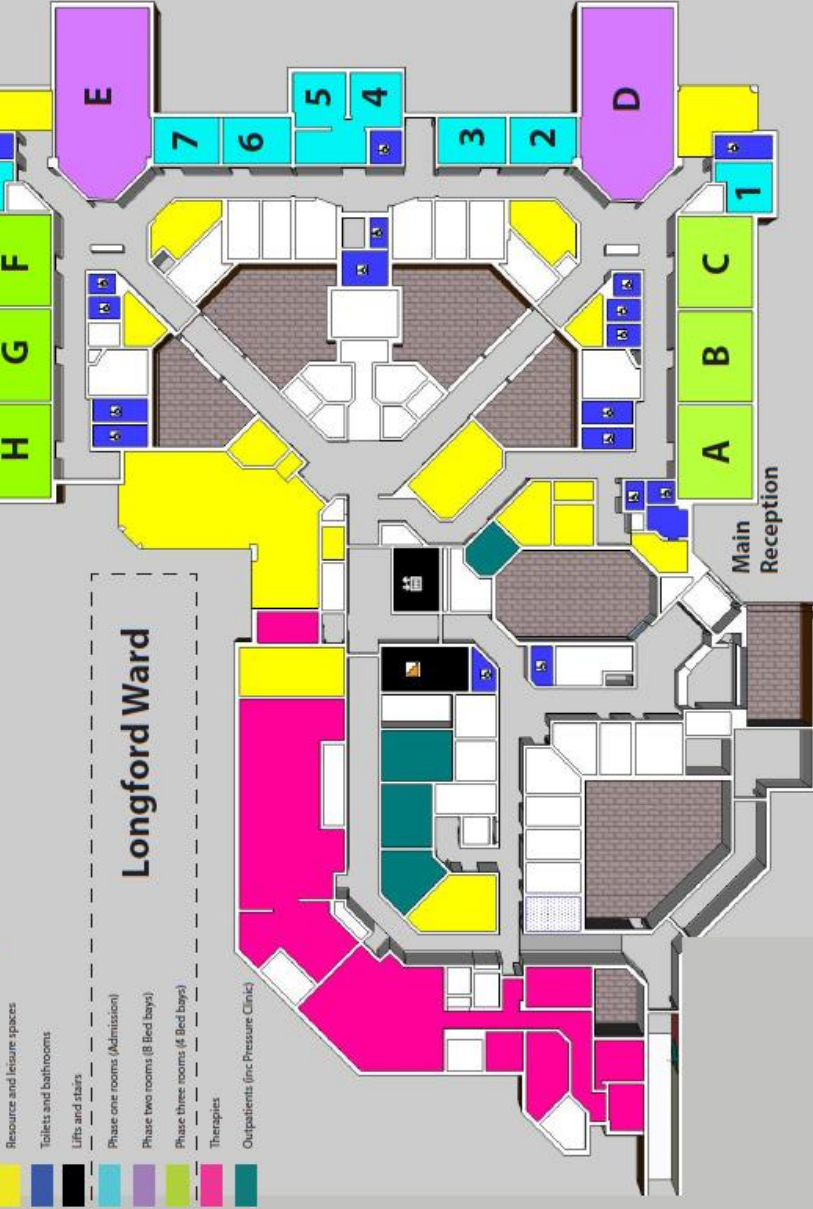


[Inspire](#) are a unique, specialist charity which raises funds to address independence and quality of life after spinal cord injury (SCI). Our [National Scientific Committee](#) and [Board of Trustees](#) approve and then fund our [Current Research Programme](#) which consists of 10 projects throughout the UK, costing **£1.6 million**. With no Government or NHS funding support, we are generating all necessary funds.



[Wheelpower](#) is the national charity for wheelchair sport, providing opportunities for disabled people to play sport and lead healthy active lives. Salisbury Spinal Centre has a Wheelpower physical activities advisor who visits every week. They have a wide range of resources and can support you by advising on physical activity and help link into local activity services and clubs for life after discharge.

# Salisbury Spinal Rehab Centre





The first [Horatio's Garden](#) opened in 2012 at the [Duke of Cornwall Spinal Treatment Centre](#) at Salisbury District Hospital.

Horatio's Garden is named after Horatio Chapple, who was a volunteer at the Duke of Cornwall Spinal Treatment Centre, Salisbury, in his school holidays.

Horatio and his father David Chapple – a spinal surgeon at Salisbury Hospital – came up with the idea for a garden and Horatio drew up a questionnaire to find out what the patients wanted.

Tragically, Horatio was killed at the age of 17. There followed an outpouring of love and goodwill, with donations flooding in for his garden to be created.

Spinal cord injuries are traumatic, life-changing events. Patients often have little or no access to the outside world during their hospital stay. However, research shows that being in contact with a natural environment contributes to an improved sense of wellbeing, which can have a positive impact on patient rehabilitation.

Cleve West designed the first Horatio's Garden. He was the perfect man

for the job. He knew the spinal centre well because his best friend had been a patient there and also won Best in Show at the RHS Chelsea Flower Show in 2011 (he went on to win again in 2012).

Cleve used Horatio's patient research as the starting point for the design and then listened to the views of everyone involved – patients, nurses, therapists, doctors and managers. He even asked us to take him around the site in a hospital bed and a wheelchair to get a patient's perspective. The garden is in fact designed to be accessible in a wheelchair or a hospital bed so that all patients are able to enjoy it.

The garden has also been designed to be enjoyed through all of the seasons. It's ever changing throughout the year and always colourful and vibrant. There are covered areas and enclosed areas as well as a wheelchair accessible greenhouse and raised flower beds.

It's an area of tranquillity and calm away from the clinical environment of the ward.







## Section 2

Respiratory Complications after Spinal Cord Injury	2. 1
Skin Care after your Spinal Cord Injury . . . . .	2. 9
Managing your bladder . . . . .	2. 21
Managing your Bowels . . . . .	2. 34
Sexuality after your Spinal Cord Injury . . . . .	2. 51



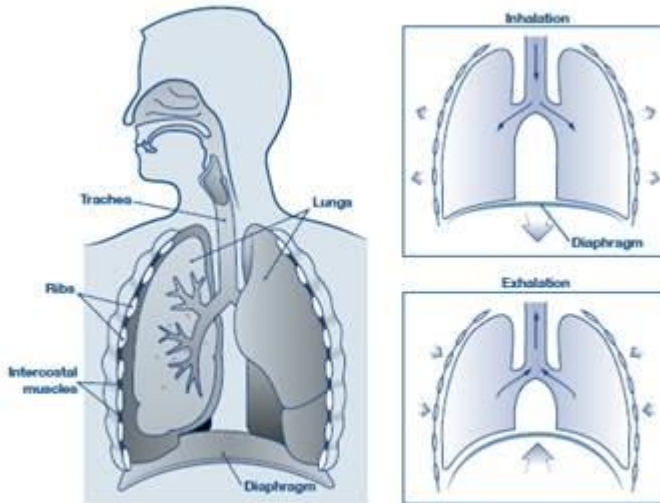
## Respiratory/Breathing Complications after Spinal Cord Injury

### 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 then passes from the alveoli into your blood stream and carbon dioxide is passed back from your blood into your lungs and you then breathe it out through your mouth and nose.

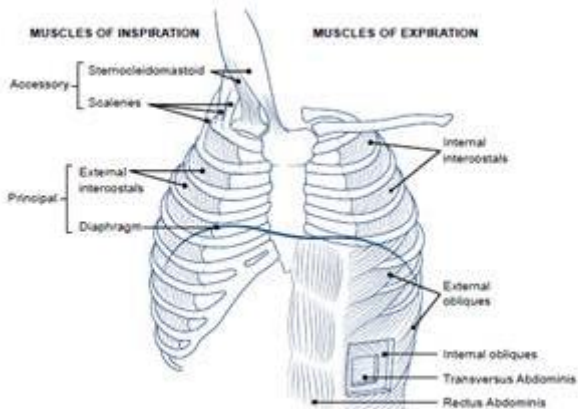
Healthy lungs produce a small amount of mucus (phlegm) which we clear each day without even thinking about it. The main role of this mucus is defensive as it protects your lungs by trapping any potentially dangerous material.

Respiratory muscles move your chest and ribs to allow you to breathe in and out. There are also particular chest and belly muscles that enable you to cough and sneeze to clear your lungs and these can be affected by spinal cord injury just like the muscles in your arms and legs (see Figures 1 and 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 of these muscles).



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

**Figure 2 – Different muscles involved in breathing.**



(a) Inspiratory muscles and their actions (left)  
expiratory muscles and their actions (right)

Table 1 - Muscles of the respiratory system.

Muscle	Spinal Nerve	Normal Function	After Spinal Cord Injury
Diaphragm	C3-C5	Contracts downwards to lengthen your thorax which pulls air down into the lungs	If your diaphragm doesn't work well enough, you will need a ventilator to breath
External Intercostals	T1-T11	Lifts your ribs 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 other breathing muscles are weak
Abdominals	T6-12	Contract powerfully during a cough to help force air out of 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-T11	Push your rib cage down and in to compress your lungs to push air out.	Weak cough.

## Am I likely to have problems with my breathing 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 and/or coughing.
- 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

## 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 breathe through a tube.

The tube may be inserted into your mouth or nose before passing down your trachea or windpipe 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 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 and is called weaning.

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 staff 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 and cause a chest infection. This is called aspiration.

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

Unfortunately for some people, they may always need support from a ventilator as the diaphragm is not strong enough to keep you breathing. If this is the case, we will use a small

portable ventilator 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 breathe 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 or chest physiotherapy. This is where various assistance is given such as shakes over the rib cage to loosen your mucus. A "Cough Assist" and/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 staff 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. Finally make sure you stay well hydrated as this will stop any chest mucus from becoming thick and difficult to clear.

## 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 of 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 specialist 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 ulcers, bed sores or pressure sores).

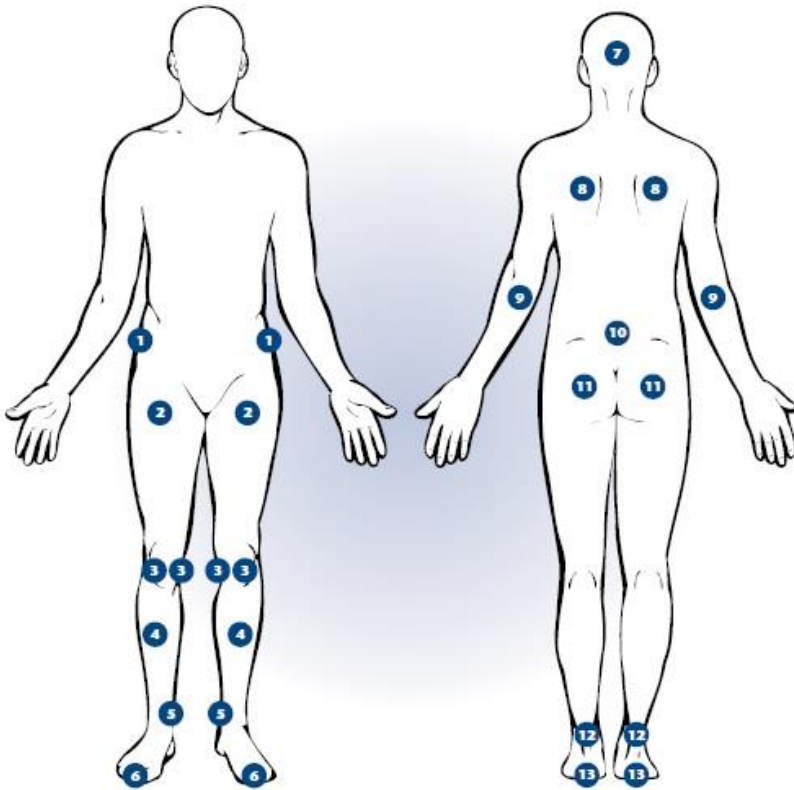
#### What is a pressure ulcer?

A pressure ulcer 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 ulcers and how can I prevent them?

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

### 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, leaning side to side or forwards 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 ulcers. 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 Wheelchair service 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 or two sizes 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. A wedding ring is fine. Their fingernails should be kept short.

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 ulcers can take a short time to form and a long time to heal. The good news is you can prevent pressure ulcers if you find them quickly and take immediate action. Unfortunately, if you ignore them, then they can be life threatening as they can get infected.

### 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?

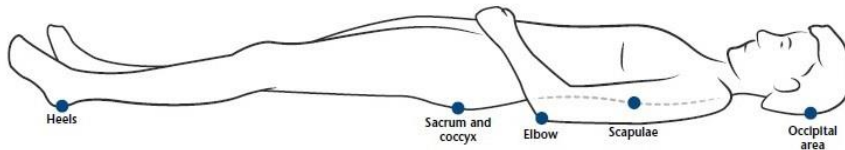
Whilst in hospital we will check your skin or encourage you to check your own skin every time you get up or return to bed. This is to establish what your skin tolerance is. By the time you go home you should know what your skin tolerance is. Routinely you should check your skin twice a day. Once before 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

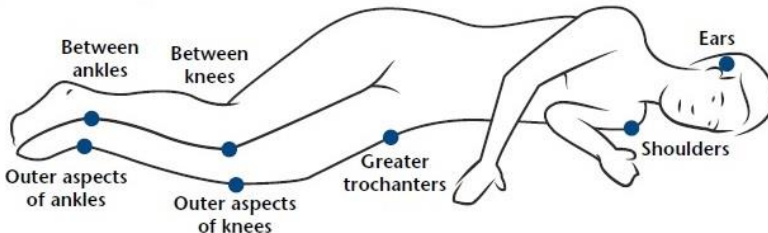
If your skin tolerance is 8 hours that means you should turn every 8 hours. If it is 6 hours, then you should turn every 6 hours etc.

### 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:



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 the 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 Centre 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 ulcer is forming you must consider going on bed rest and remain there until your skin is completely healed.
3. Always get advice from your Community nurse. The Spinal Centre Outpatient Nurses can advise you and the Community Nurses too.

### Skin

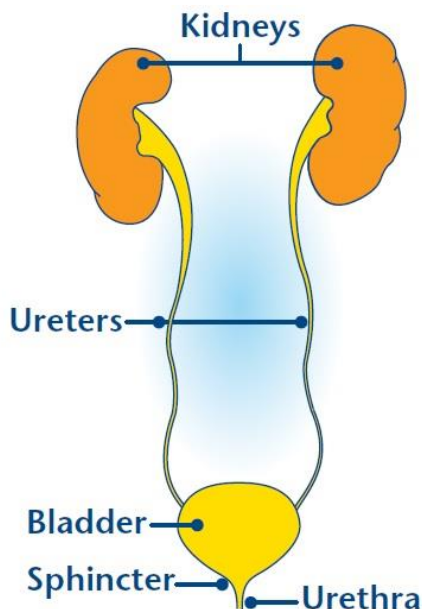
I and have had no skin problems either in hospital or since discharge but I am aware of the problems that may occur and take care of my skin in order to avoid them.

## 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

The kidneys work 24 hours a day filtering the blood that passes through them to get rid of waste products, thus producing 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 and doctors 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 Urethral Catheter

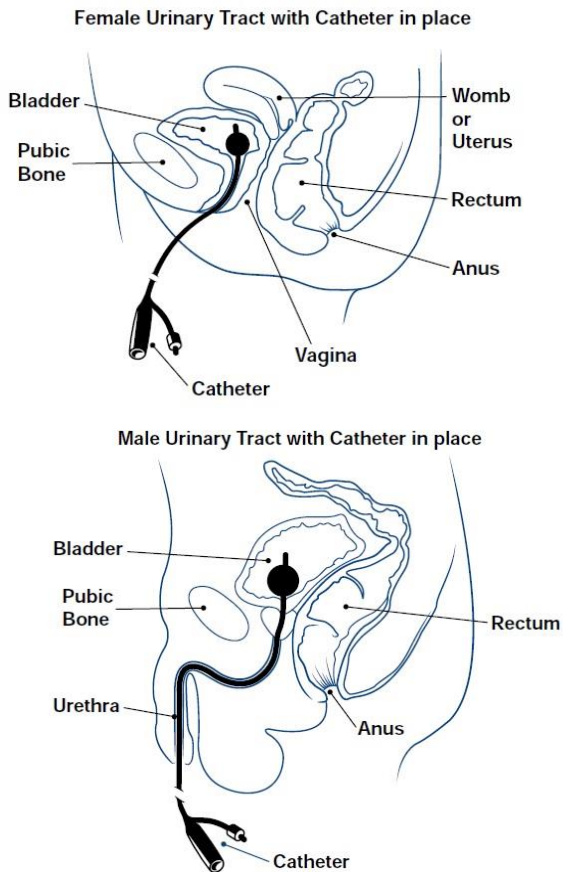
This catheter is inserted into the bladder through the urethra. Once inserted, a small balloon is inflated with water to keep it in place. A catheter bag is attached to the catheter which can be worn on the thigh or calf.

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



### 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.

At first the Nurses or the District Nurse will do the first change of the suprapubic catheter after 8-12 weeks from the insertion. Then after this,

a nurse or your trained carer will then change your catheter. We recommend this catheter is changed every 6 weeks.

We may teach you or your carer how to change the catheter.

If you have a problem or blockage before the first suprapubic change, we advise that you phone the District Nurse to insert a urethral catheter and spigot the Suprapubic catheter. This is to ensure that the new suprapubic catheter keep a good tract for when it's due for its first change. You will then drain your urine through the urethral catheter.

Once you have had the first suprapubic catheter change, the urethral catheter can be removed.

### 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 4-6 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.

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

### Sheath/Condom 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 1-2 days to prevent infection and can be used with intermittent catheters.

## Using a Catheter Valve

A catheter valve is a tap-like device, which fits into the end of your catheter (urethral or suprapubic). This can then be attached to a urinary drainage bag so that the valve lies between the end of the catheter and the drainage bag. The valve may be opened or closed/switched on or off to drain urine from your bladder or to stop drainage. Various types of taps are available. The best type will be chosen for you depending on how good you or your carer is at operating it.

Most patients who have a long-term catheter now use catheter valves. It is generally felt the bladder should not be kept empty at all times, because it has been shown that this reduces bladder capacity and tone.

The aims of using a catheter valve are:

- To get your bladder used to holding a volume of urine again.
- To improve the capacity of your bladder.
- To get your bladder to hold between 300-500ml of urine.
- To have faster flow of urine to aid drainage of bladder debris.
- To have the catheter valve closed off all day and for you to drain your bladder 4-5 times per day by opening the valve for a couple of minutes (or until drainage stops).

Because of the risk of urine leakage, and autonomic dysreflexia, we suggest that you follow the regime below. You may need to discuss with your consultant whether you need to take medication (such as detrusitol, solifenacin or oxybutynin) to reduce the chance of urinary leakage.

Date		
	<p>Days 1 &amp; 2  Because of the risk of urine leakage, and autonomic dysreflexia, we suggest that you follow the regime below. You may need to discuss with your consultant whether you need to take medication (such as detrusitol, solifenacin or oxybutynin) to reduce the chance of urinary tract infection.</p>	<p>Close the valve off for 30 minutes three times a day i.e. to stop the catheter from draining. After 30 minutes open the valve and leave the catheter to drain freely.</p>
	<p>Days 3 &amp; 4</p>	<p>Close the valve for 1 hour, 3 times a day.</p>
	<p>Days 5 &amp; 6</p>	<p>Close the valve for 1 hour 30 minutes, 3 times a day.</p>
	<p>Days 7 &amp; 8</p>	<p>Close the valve for 2 hours, 3 times a day.</p>
	<p>Days 9 &amp; 10</p>	<p>Close the valve for 2 hours 30 minutes, 3 times a day.</p>
	<p>Days 11 &amp; 12</p>	<p>Close the valve for 3 hours, 3 times a day.</p>

	Days 13 & 14	Close the valve for 3 hours 30 minutes, 3 times a day.
	Days 15-16	Close the valve for 4 hours, 3 times a day.
	Days 17-18	Close the valve for 4 hours 30 minutes, 2 times a day.
	Days 19-20	Close the valve for 5 hours, 2 times a day.

## Problems that can arise with catheters

Common Problems	Signs and Symptoms	Treatment
<p>Urinary Tract Infection</p> <p>(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 heartbeat)</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>Blocked Catheter (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</p> <p>(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.</p> <p>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>



Common Problems	Signs and Symptoms	Treatment
<p><b>Reflux of Urine</b></p> <p>Reflux is when urine flows back up to the kidneys. This can cause infection to spread to your kidneys and over time may cause permanent damage.</p>	<p>Swollen abdomen</p> <p>Feeling nauseous</p> <p>Recurrent urine infections</p> <p>Dysreflexia</p>	<p>Having regular urological check-ups will pick up on conditions such as reflux of urine.</p> <p>If you are diagnosed with reflux of urine, it would be one of the main reasons for changing your bladder management</p> <p>It is important not to overfill / overstretch the bladder and ensure that the bladder is emptied properly.</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 Outpatient Team 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

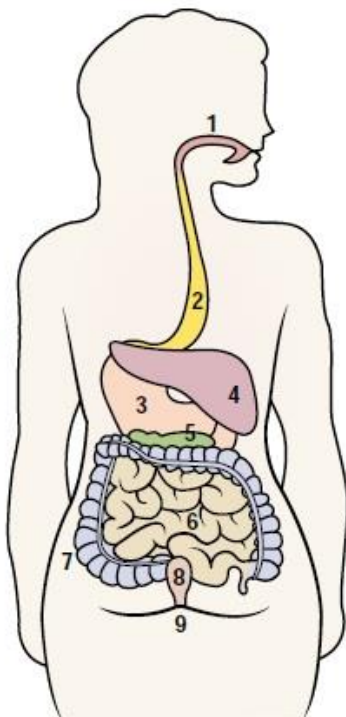
Muscles, in a process called peristalsis, push the food down into your stomach

#### 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 y 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 messages 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.

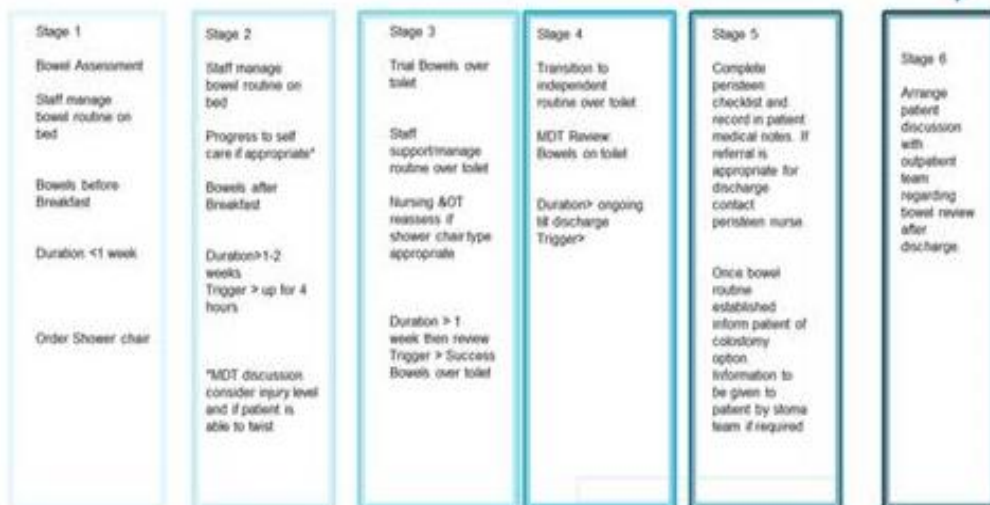
The two most important components of a good bowel routine are diet and timing.

The Spinal Centre has developed a Bowel Care Pathway to give some structure to the various stages of progression with your bowel care.

This will help you to have an understanding of how your bowel care will be managed and also what advice is available to you when you are discharged. It's important to us to ensure you are well informed of this process.

# Bowel care progression Pathway

Patients can move between the stages depending on their individual needs



## 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 curtains 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 fingernails 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 levels.
- 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/Laxido:

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!

## The future: There are options

Many people will establish their bowel routine as described above and stick with it for many years. However, there are options available to you to consider. Once you are established into a regular bowel routine, you can then think about the options that are available to you for managing your bowels.

### **Peristeen**

Peristeen is the recommended Bowel management device for people with Spinal injuries, which can allow you to develop a fast and effective bowel routine and achieve a good and effective result, if used regularly.

Peristeen has been reviewed and recommended by NICE (The National Institute for Health and Care Excellence), the NHS body that reviews clinical effectiveness.

Peristeen empties the bowel by introducing water into the bowel using a rectal catheter. It is performed whilst sitting on the toilet. The water stimulates the bowel and flushes out the poo, leaving the lower half of the bowel empty. Peristeen empties the bowel so efficiently, that it can prevent incontinence and constipation for up to two days.

Peristeen has been proven to reduce time spent on bowel management and improve your quality of life.

If it is right for you, we usually arrange for you to be started on

Peristeen once you have been discharged and can help you learn in your own environment. You will have the chance to meet a specialist nurse to discuss this during your stay.

## **Colostomy**

A colostomy is a small opening on your tummy where part of your bowel (colon) is brought through the surface during an operation. Poo will then passively exit through the opening and be collected in a discreet colostomy pouch.

A stoma has the advantage that is quick and easy to manager yourself even if you have limited dexterity. A stoma works well for people looking to regain a sense of control of their bowel routine and who want to reduce the impact bowel care has on their ability to work, holiday and socialise.

If you are interested in finding out more about having a colostomy you will have the chance to meet a specialist nurse to discuss this during your stay.

## **Lifelong Care**

It may feel a long time until you are due for discharge from the centre. Your stay with us will prepare you and those involved in your care, with the skills needed to keep you regular when you leave us.

It's natural that when you leave us that you will adjust your routine to start to fit your life. Do try and stick to your bowel management routine – this will help you prevent problems.

We will continue to ask you about your bowels as part of your routine Outpatient appointments. If you are struggling with your routine, you should make sure that you mention this. You should mention if:

It's taking longer than 30 minutes to complete your bowel routine.

Bowel accidents are becoming a regular problem.

You are constipated. (Your poo will be harder, and you will have bowel movements less frequently)

If you are having episodes of Autonomic Dysreflexia when you manage your bowels, or in between

You would like to explore the option of Peristeen.

You would like to explore the option of a Colostomy.

If you don't have a routine appointment planned – we provide a Bowel Review service that you can contact us if you experience any issues. You can contact the Outpatient nurses that run the service on:

Tel: 01722 429291

Or Email: [sft.spinalopnurses@nhs.net](mailto:sft.spinalopnurses@nhs.net)

## 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, possibly 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 can recover a positive outlook on life. You will find that you can 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) may 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 physical 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 centre runs a Sexual Function clinic and works closely with the Fertility Centre.

### 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**

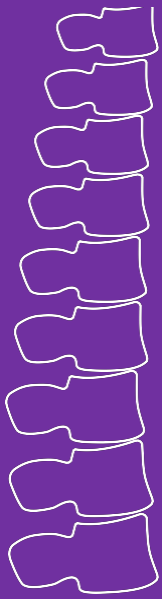
This occurs only in people with a spinal cord injury at T6 or above. You will have been taught the common causes of Autonomic Dysreflexia. Occasionally it can also happen through sex. If you experience any of the symptoms of Autonomic Dysreflexia during sex, you should stop immediately, sit upright if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

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

### **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

- Staying Fit and Well after Spinal Cord Injury . . . . . 3. 1
- Autonomic Dysreflexia . . . . . 3. 8
- Muscle Spasm . . . . . 3. 11
- Neurogenic Pain . . . . . 3. 13
- Upper Limb or Hands Splints . . . . . 3. 14
- Foot care Advice . . . . . 3. 16
- Temperature Control . . . . . 3. 18
  - Functional Electrical Stimulation . . . . . 3. 19



## Staying Fit and Well After Spinal Cord Injury

As you will be aware, your body undergoes a number of changes after spinal cord injury (SCI). When muscles don't function, a process called deconditioning occurs, in which your body becomes accustomed to reduced levels of activity. The reduction in the amount of working muscle tissue has effects both locally in the paralysed limbs and globally throughout your body, which start within 24 hours of injury and can settle down after 6 to 12 weeks. Many of these effects can be limited by proper management on your part, however. 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

The cardiovascular system is made up of the heart and blood vessels. It carries oxygen and nutrients to all of your other body systems. As in the general population, cardiovascular disease is one of the biggest causes of death for people with SCI; and like the general population, we recommend regular exercise of moderate intensity for 30 minutes at least, 3 to 5 days of the week for those with SCI, to maintain and improve cardiovascular fitness.

People with SCI are usually less active than the general population. Apart from restricted movement ability, this can be due to other issues such as access problems or a lack of knowledge about what community activities or resources are available. Over time, reduced demands on the heart caused by lower levels of activity cause the cardiovascular system to become deconditioned. This will make you less fit and you may feel that you have little energy or become breathless on 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. Over time however, many people find that their weight gradually creeps up, possibly to more than before your injury. This is because you may continue to eat the same amount as before your injury but are less active than you were. If you put more energy into your body than you use 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 risk of injury as the load on your arms is increased. Gaining weight over your hips and legs will make leg handling more difficult and may cause your hips to rub against the side or wheels of the wheelchair which can lead to skin issues.

Whilst losing weight after a SCI can be more difficult than before, it can be done through sensible eating and increasing 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.

### 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 (breaking) so you

need to be careful when handling your paralysed limbs and positioning them for transfers. The outpatient clinic may arrange for a DXA scan to check your bone density. You can minimise bone density loss to some extent by standing regularly or through certain uses of Functional Electrical Stimulation (FES)

### Joint Stiffness

The joints and muscles of your limbs will stiffen and may permanently shorten if you do not move them regularly through range or stretch them. 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 in joints that have one strong muscle and one weak muscle acting on them – for example, strong biceps and weak triceps often cause the elbow to remain in a bent position.

Keeping a good range of movement can help with becoming more independent with your everyday activities; the opposite also applies - 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 it is possible to have stretching included in 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 can assess you for the use of a standing frame at the Spinal Centre. It is important to note that standing frames are not always available in the community. If appropriate you will be referred to your community team for provision of a standing frame following discharge; this will be dependent on a number of factors such as your level of injury, local availability, space for equipment and availability of assistance to use a frame.

Regular use of a standing frame may help to manage muscle spasm, reduce the amount of bone density loss, 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. To get these potential benefits from standing it is recommended that you stand for a minimum of 30 to 60 minutes, 3-5 times per week.

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, but we would recommend discussing this with a therapist. These will not be supplied by your wheelchair service.

## How can I exercise?

Whilst in the spinal cord injury centre you will have equipment and support available to you for exercise, but things will be different when you leave. There are still lots of options to staying fit out in the community, however.

You do not always need ongoing physiotherapy after you leave the spinal centre and there are lots of other ways to keep working on getting stronger and fitter. One of the biggest difficulties to overcome may be motivating yourself to stay active.

Many solutions can evolve with readily available 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 as you are able to. This will benefit your fitness and arm strength. Be aware of long-term shoulder wear and tear however. You are advised to discuss this with your physiotherapist.
- 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.
- See what facilities there are at your local gym – some have wheelchair accessible weight and resistance training equipment and arm bikes.
- If you have reduced hand function, buy some grip aid gloves – you can use them with dumbbells, other weights or for arm bike handles. Crepe bandages wrapped around your hand could be used as an alternative.
- Find a workout 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.
- Contact 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.
- 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.
- 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. Your physiotherapist may be able to introduce you to the gym and to the fitness staff to show them how to help you.

Below are some website suggestions for 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 01722 336262 Ext 2455

## 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 5mg or GTN spray for patients who are aged 60 years and above. If symptoms remain despite taking Nifedipine or GTN spray contact your doctor.

It is important to have sublingual Nifedipine or GTN spray 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. Any touch, movement or irritation can trigger and sustain spasms.

Mild spasm may be beneficial in helping to maintain muscle bulk, bone strength and reducing osteoporosis, they help maintain circulation and can even assist transfers. Severe spasm, however, may be very disruptive to everyday activities, wellbeing and mood.

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

- Pressure ulcers
- Ingrown toenails
- 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.
- Standing may help to reduce spasm if a standing frame is appropriate and available.
- Lying on your stomach for half an hour a day can achieve the stretch standing gives without weight bearing.
- Keep as active as you can.
- Maintaining good eating habits can help prevent infections, constipation and pressure 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, working with the Orthotics team if appropriate. 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).

### Wrist Supports

These are usually prefabricated 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 and your skin will be checked. If there are no concerns regarding pressure, over the next 3 to 4 days you should gradually build up the time until you can wear the splints overnight. Each case is individual, and your therapist will give you advice regarding how and when to wear your splints.

### 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.

## Foot care Advice

Maintaining good foot care and hygiene is important. It is essential that you pay attention to the skin of the feet and your toenails. 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 washcloth 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 your 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 toenails

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 a cream/moisturiser. 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 toenails 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.

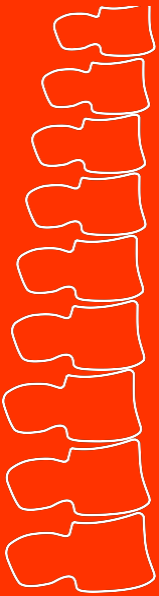
## Functional Electrical Stimulation (FES)

FES is small pulses of electrical stimulation to the nerves that supply paralysed muscles. The stimulation is controlled in such a way that the movement produced provides useful function.

FES can be effective (in some cases) **where movement has been lost** due to spinal cord injury, for the following purposes:

- For strengthening weak muscles
- For increasing range of movement
- To improve sensory awareness
- To assist in regaining function

Your therapists may use FES as part of your therapy treatment if it is appropriate for your individual situation.



## Section 4

- Discharge Planning . . . . . 4. 1
- Housing . . . . . 4. 3
- Education and Employment . . . . . 4. 5
- Wheelchair Maintenance . . . . . 4. 9
- Spinal Outpatient Clinic . . . . . 4. 11
- The Role of the Spinal Nurse Specialists . . . . . 4.
- Short Stay Assessment . . . . . 4. 19



## Discharge Planning

Discharge Planning starts almost immediately. A provisional discharge date of 12 weeks hence is set for all acute admissions to the Spinal Unit. This is reviewed at regular intervals by the Multi-Disciplinary Team consisting of the nurses, Occupational Therapist (OT), Physiotherapist (PT), Consultant, Psychologist and Discharge Coordinator.

As discharge planning issues such as housing and care can be time consuming to sort out it is essential that discharge planning starts as quickly as possible after admission in order to aid a seamless transition from hospital to an appropriate discharge destination.

The team working with you will meet with you regularly to set goals with target dates and to review the estimated date of 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:

Before your official discharge date, the Discharge Coordinator, Occupational Therapist and Nurse will liaise with your local Community Nurse and Community Occupational Therapist to make sure all appropriate equipment is in place.

If a care package is required to assist with hoisting, meals, washing or dressing, a referral will be made (with your consent) to your local social services. They will then arrange the appropriate care for discharge. If you have a very high level of care needs, then a Continuing Healthcare assessment may be carried out. This does not always happen while you are in hospital and the process varies depending on which county you live in. Your Discharge Coordinator will explain this process to you, if it is required.



## 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 Outpatient Nurses on 01722 429291 or the Community Liaison Clinical Nurse Specialist on 01722 429130 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 downstairs living.
- 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/building works 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.
- 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.

If your home is not suitable for you to return, or needs major adaptations, your local social services will need to seek temporary accommodation (interim placement) for discharge until new suitable accommodation can be sourced, or until building works are completed.

## 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.

A regular Vocational clinic is organized by OTs in partnership with SIA Vocational Advisors, to enable you to explore all aspects of returning to work or education, including signposting to other advice services. Your OT will be happy to arrange an appointment for you.

### 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. Should you plan on returning to your original educational establishment on discharge, your occupational therapist will discuss this with you and support you as appropriate.

### 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 will have the opportunity to meet with a local Department of Work and Pensions representative who will tell you what support is available through their service. 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 liaise 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. In some circumstances the occupational therapists may be able to 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.

## Information on Posture and Seating Equipment

### In Hospital

During the time you are here in the Spinal Centre we provide you with a suitable wheelchair and cushion for your rehabilitation. This equipment may be different from equipment that will be provided for use out in the community. We are unable to provide any posture and seating equipment for use at home once you are discharged from hospital.

### At Home

The NHS provides people who need a wheelchair and cushion in the community with an appropriate wheelchair via a network of service providers, often referred to as “wheelchair services”. Each Wheelchair Service covers a designated geographical area. During your rehabilitation referrals may be made to this service by the Spinal Centre staff.

### The Spinal Centre posture and seating service

Before mobilising out of bed for the first time an assessment will be carried out to determine the equipment you will need to participate in your rehabilitation programme. This usually comprises of a cushion and a wheelchair.

### Equipment for use in hospital

Your therapy team in conjunction with the Rehabilitation Technician and Engineer will meet with you at appropriate intervals during your rehabilitation to assess your posture and fine tune the equipment we have loaned you. It is not always possible to achieve a perfect match between the equipment we have in stock and a person’s specific situation.

## Equipment for use at home

We will work with you and your local wheelchair provider to establish appropriate posture and seating equipment for discharge out into the community. This often involves a wheelchair specification being produced and sent onto your local Wheelchair Services. Wheelchair Services will then review the results of our assessments and recommendations, along with the equipment available to them, and decide what equipment they can supply you with for discharge home.

The assessments for your initial wheelchair and cushion usually take place at a time when your spinal cord injury maybe continuing to change. It is therefore often agreed that the equipment supplied by your Wheelchair Services for discharge will require further assessment by your Wheelchair Services out in the community and in the environment, it will be used. We often refer to equipment for discharge as your 2interim wheelchair. On discharge you may need to contact your Wheelchair Services to arrange follow up and review of your equipment provision options.

## 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.

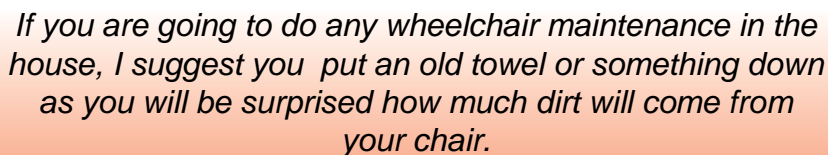


You can also clean out the front castors by using a pair of tweezers or something similar. You can use pointed tweezers to pick out strands of hair one at a time, which will take a bit of time but will also let you get every bit out.

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.



*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.*

## Spinal Outpatient Services Clinic

Outpatient Services is staffed by a Multidisciplinary Team who have expertise in the long-term care of spinal cord injured patients. The Spinal Centre Outpatients Department offers outpatient clinics for the follow up of people who have sustained a spinal cord injury. Discharged patients are given their first appointment within 10 – 12 weeks from the date of their discharge. Following this review Outpatients are seen in review clinics yearly, every 18 months or every 2 years, depending on their individual needs. Spinal Centre outpatients are followed up for life. Some outpatients may opt not to be followed up by the Spinal Centre, in which case they are discharged from the Spinal Centre outpatient caseload and their GP is informed.

There are a range of specialist led general clinics as well as more specific focus clinics as follows:

### Routine Review Clinics

At routine review clinics the following are assessed and reviewed: bladder, kidney function, bowel, skin, pain, spasm, sexual function/fertility, psycho- social, neurological status, contractures, autonomic dysreflexia, renal ultrasound, abdominal X-ray and functional abilities/changes.

## The Outpatient Service

The outpatient team is available for advice from the patient and Healthcare Professionals involved with your care. They will liaise with the local Community Nurses, Tissue Viability Nurses and other healthcare professionals offering advice and support as appropriate. You may be referred to other disciplines as necessary, either at the Spinal Centre or to other agencies. This offers a holistic assessment of the patients' needs and advice about treatment options, including wound management, seating and mattress advice. If further advice is required or surgical intervention is suggested, your GP may be requested to refer you to a Plastic Surgeon. The team will also address the cause(s) of the pressure ulcer and how the development of future ulcers can be prevented. Wherever possible the patient is followed up by the team, while liaising with the Community Teams to ensure continuity of care.

## Outpatient Nursing Service

The Spinal Outpatient Nurses provide lifelong 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. Your outpatient care will be delivered by a member of the specialty team and could be via a virtual consultation or if clinically indicated a face to face consultation. The clinics are held by the nursing team and the medical team.

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.

### The Pressure Clinic Service

The service aims to ensure that seating continues to be assessed. If problems occur, further assessments can be arranged for the patient to attend the Pressure Clinic and can be done through the Outpatient Nurses or by contacting the Pressure Clinic to arrange an appointment. The Pressure Clinic staff liaises with patients' local 'Wheelchair Service' about seating assessments and cushion recommendations. Pressure mapping is carried out, when appropriate, to record interface seating pressures which enables cushion, seating and posture to be reviewed. In addition, staff educate patients, relatives and carers about the development of pressure ulcers and how to prevent them. This is discussed in relation to seating, bladder and bowel management and activities of daily living. A telephone advice service is also available. Ex 4921

### Occupational Therapy Service

Services offered include wheelchairs and seating including manual or powered products, equipment to assist with everyday life, hand management and splinting, help and advice with ongoing equipment loan, driving/transport advice, work/training/leisure advice, change in function assessment, home visits and advice in regards to upper limb surgery.

### Physiotherapy Service

Services offered include seating and posture, spasm management, standing advice and equipment, exercise programmes, change in function, gait assessment and review of orthotic requirements if provision or replacement is needed.

## Respiratory Service

Respiratory Specialists provide telephone support to ventilated patients and their care teams or community staff about equipment, training and care, and other clinical issues. They are available for specialist spinal advice regarding respiratory problems following discharge from the Spinal Centre.

## Posture Assessment Service

The Posture Assessment Service is held by Outpatient Physiotherapists and Occupational Therapists with input from the Rehabilitation Engineer and Medical Engineering as appropriate. Providing an in-depth assessment of posture and seating equipment. The therapists liaise with Wheelchair Services to discuss provision of alternative equipment.

## Sexual Function Clinics

A Sexual Function clinic is Held in the Outpatient Departments. Which address the assessment and management of erectile dysfunction and fertility, including retrieval of sperm.

## Respiratory Outpatient Service

This service is staffed by a specialised team. Patients that are seen are those who have a tracheostomy, who are ventilated, or have other respiratory issues.

## Video-urodynamic Clinics

There are 3 clinics per week staffed by a Specialist Radiographer and an Outpatient Nurse. Results of the test are discussed in the multidisciplinary urology meeting for further management plans. You will be informed of the outcome by letter.

## Assessment and Management of Chronic Bowel Problems

Patients are referred to the Outpatient Staff Nurse. A holistic assessment is carried out identifying care needs, agreeing interventions and implementing an action plan to address the problems. Bowel diaries are kept for 2 weeks by the patient; these are sent to the Registered Nurse who can alter the bowel regime as necessary. Follow up continues until the problem is resolved.

## Spinal X-ray Service

This is staffed by Radiographers who also provide radiography services to the Spinal Centres inpatients. The department is fully wheelchair accessible and staff are experts in the manual handling of patients. At a routine appointment the patients attend Spinal X-ray for a renal ultrasound and abdominal X-ray. The results are immediately available for the Consultant to review and compare with previous results.

## Telephone Advisory Service

This service is offered to outpatients, their relatives, carers, Community Nurses, General Practitioners, Wheelchair Services, Continence Nurses, staff in General Hospitals and Nursing Homes. Advice is given about all aspects relating to living with a spinal cord injury in the community and referrals are made as necessary. Ex 4291. People can also be put in touch with external agencies such as the Spinal Injuries Association, Back Up etc.

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 NHS 111.

## Musculoskeletal Pain and Spasticity Service

Patients with musculoskeletal problems, pain and/or spasticity are reviewed by a Consultant and a Therapist (when appropriate). Problems are identified and managed appropriately to prevent complications.

## Intrathecal Drug Delivery System (IDDS) Service

Patients who require intrathecal drug therapy are identified by carrying out a trial and by multidisciplinary assessment. Implantation of an IDDS, post-operative management and follow-up appointments for refills are a part of this service

## Your Appointment

What to bring with you:

- Your appointment letter
- A note of your current medication

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

Some patient appointments may take longer than expected.

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 01722 429 084.

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 hospital patient transport, you need to liaise with your GP in order to facilitate this.

## Important Telephone Numbers

Spinal Booking Co-ordinator – 01722 336262 Ext 4084

Spinal Outpatient Nursing Team – 01722 336262 Ext 4291



## Short Stay Assessment

Rehabilitation following a spinal cord injury is a lifelong journey. As a Spinal centre, we are striving to improve the care of those patients who have not been able to participate in an Inpatient programme.

Those whose family/social support would make it difficult for them to commit to a lengthy admission to the spinal centre may be offered alternative options such as a multidisciplinary day assessment or planned short rehabilitation programme.

You may be offered the opportunity to undertake a short stay inpatient assessment admission so we can fully assess your needs and make a plan for the future to enable you to live well after spinal cord injury.

We aim to work closely with your local Community services to educate and help facilitate the care you need following your spinal cord injury.

**We must stress, the purpose of this admission is for assessment purposes only. During this short stay, we are unable to offer a full rehabilitation programme.**

What can I expect?

- Up to a three-day short stay inpatient assessment

What will be assessed?

All aspects of your spinal cord lesion including:

- Bladder function
- Bowel function assessment
- A joint Physiotherapy and Occupational assessment
- Mobility and equipment
- Driving/Vocational support
- Your home life

## What shall I bring?

- Your usual medications
- Mobility aids i.e. wheelchair, frames, sticks
- Comfortable clothing
- Toiletries

## What will happen when I'm discharged?

- We will make arrangements to see you in Outpatients Department in the Spinal Centre as part of our lifelong follow up for patients under our caseload.
- We may refer you to community services to support you at home such as District Nurses, your local Wheelchair Services.
- We will give you guidance and information regarding your injury to help you manage at home.
- We may invite you back to the Spinal Centre for other day appointments such as posture or sexual function.
- We will make suggestions how to manage your bladder and bowels in the long term.
- We will continue to give you telephone advice and support.



## Section 5

- Information about Driving . . . . . 5. 2
- Transport . . . . . 5. 10



## Information about Driving

For many people, using transport or being able to drive following spinal cord injury can be a daunting prospect. However, the freedom of a car may be considered essential rather than a luxury for wheelchair users. For those considering a return to driving, here are some frequently asked questions. More in-depth information can be sought from the DVLA, your local driving assessment centre or the Motability Scheme.

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

[www.drivingmobility.org.uk/about/](http://www.drivingmobility.org.uk/about/)

<https://www.gov.uk/browse/driving/disability-health-condition>

When thinking about a return to driving, you must consider a number of points and you may need to attend an appointment at a driving assessment centre to establish which modifications you require in order to safely control a car. This assessment is not a driving 'test'.

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

Yes, if you have had a spinal cord injury you are required by law to tell the Driving and Vehicle Licensing Agency (DVLA) before you resume driving. Failure to do so can lead to prosecution and may invalidate your insurance. There are a series of standard forms to complete, including a consent form to allow the DVLA to contact appropriate medical staff in relation to your medical status. The DVLA may request that you send your license to them to enable them to amend it. If you know you are going for a driving assessment it is useful to ask whether it can be forwarded at a later date as you will need your license with you for your assessment.

[www.gov.uk/spinal-problems-driving](http://www.gov.uk/spinal-problems-driving)

[www.gov.uk/driving-medical-conditions](http://www.gov.uk/driving-medical-conditions)

[www.gov.uk/reapply-driving-licence-medical-condition](http://www.gov.uk/reapply-driving-licence-medical-condition)

You will also find information on vehicle tax and the Blue Badge Scheme on the DVLA website.

Driving assessment centres will have the most up to date guidance to help you with the process for returning to driving.

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

If your injury has resulted in complete paraplegia with no other injuries, you are unlikely to need a formal assessment. An automatic car with hand controls may be the most suitable option and your final choice of vehicle and controls must be the result of a thorough trial. There are different types of hand controls available depending on your balance and dexterity.

A common hand control product is a push and pull accelerator/brake but there are many configurations.

If you are eligible to apply for a car through the Motability Scheme, choice of hand controls and the associated cost implications will also need to be considered.

Steering aids (steering balls or grips) are available in various designs and it is a matter of assessing which products are most suitable for you.

Converting a manual vehicle to drive with hand controls may be feasible if you don't wish to change your car.

An appointment at a 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 may have adapted vehicles available for lessons) to give you the opportunity to practice the controls and improve your confidence.

The driving assessment centre may also have examples of equipment that could help you lift and store your wheelchair in a vehicle for you to try.

### Is using hand controls difficult?

Driving with hand controls can feel strange at first but most people adapt to it fairly quickly if they have selected the most suitable equipment to meet their individual needs.

For some people, balance is compromised, and this will vary between individuals and their level of injury.

Steering aids on the steering wheel can help with turning corners etc. and optimum positioning of the chosen product can make a difference to your balance/stability. There are also chest straps available that can be used in addition to the safety belt of the car. They are attached first, prior to putting on your safety belt.

### As a tetraplegic, will I be able to return to driving?

This will be dependent on your level of injury and the functional difficulties you experience as a result. Assessment will establish whether you have the ability to control the car confidently and safely. It will identify the adaptations that are required to help with this.

### 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 to assist you. This can also be assessed at the driving assessment centre. If you cannot transfer you may need to consider a vehicle that you can wheel into. Some people drive from their powered wheelchair and some are able to wheel into the vehicle and transfer into a 6-way multi-adjustable driver seat.

These vehicles can be expensive, and grants may be available through the Motability Scheme. Details regarding eligibility criteria 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 usually an interview with the aim of getting basic details from you and to gain further information about your injury, current health etc. It may involve a basic eyesight test and physical assessment. The staff will need to establish whether you have any visual or cognitive difficulties, or any other issue that could pose a problem when driving, such as suffering from severe spasm or taking certain prescribed medications.

The assessment may involve transferring into or wheeling up to a 'static rig' - the dashboard and driving controls of a former 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 this goes well and is within an acceptable range, you may then progress into an adapted vehicle to allow the assessor to further explore your abilities/difficulties. This also gives you a chance to 'have a go' at driving. The drive is likely to begin around the grounds of the assessment centre, followed by a short trip on nearby roads if it's deemed safe for you to do so.

When you complete the assessment, you will be advised at the time, and in writing of the adaptations that you need to enable you to drive safely. Optimum vehicle type may also be discussed. If the test doesn't go as well as you expected, a further assessment may be carried out in the future.

There are 20 main UK driving assessment centres and additional satellite centres. Each driving/transfer assessment centre will be able to advise on the process for individual assessment. They can provide details of the cost of assessment and whether you can seek help with funding.

[www.drivingmobility.org.uk/about/](http://www.drivingmobility.org.uk/about/)

[www.drivingmobility.org.uk/find-a-centre/](http://www.drivingmobility.org.uk/find-a-centre/)

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

If you have an incomplete injury and especially if you would like to use your feet to operate the pedals of a manual car, a driving assessment will be necessary. With a degree of weakness and/or reduced sensation in any of your limbs it is essential to make sure that you can safely control a vehicle. The level of weakness and any sensory deficit in your limbs will need careful consideration as well as stamina and reaction time.

### During my injury I suffered a head injury. How soon can I return to driving?

This will be decided by the DVLA in liaison with the medical professionals involved in your current and previous care. If you have experienced blackouts, memory problems, seizures, visual disturbance etc. you will especially need guidance on the timing of your assessment.

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

You must have a provisional license before you can have a driving assessment. (If you don't have one you will need to apply for 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 basic hand controls which you could access for lessons. Otherwise, you may have to provide your own adapted vehicle. You may have to fund these adaptations if you do not meet eligibility for a grant 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 do not drive and cannot transfer out of my wheelchair. What are the options for transport for me?

- Public transport – buses often have a kneeling facility and fold down ramp operated by the driver. Trains can also be accessed with ramps operated by station staff. It is worth checking with the transport company prior to travel, to check exactly what help and facilities are available.
- Taxi – hackney taxis can have ramps, but it is not always easy to get in and out or travel sideways on to the driver. It may be o.k. for short journeys but there are also wheel-in taxis with wheelchair restraints fitted.
- Dial-a- ride
- Wheelchair adapted passenger vehicles

## Additional information

If you lease a car through the Motability Scheme, breakdown cover is included.

If you don't have a Motability car, you could inform your breakdown company about your disability. They will add this to the information they already keep for you. If you should experience a breakdown, explain to the call operator that you have a disability which will help them to prioritise their attendance.

## Insurance

There should be no difference to insurance for cars fitted with hand controls. Hand controls are not seen as an adaptation to the vehicle, 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 on standard insurance policies. This could affect the cost of your insurance if you choose to leave the Motability scheme and buy a car privately. The insurance company used by Motability should be able to provide details of your insurance history to an insurance company, but they may charge you for this service.

## What do I need to consider when choosing a vehicle?

This can be very complex, and you need to consider how you will get into and out of the vehicle, how your wheelchair is lifted and stored. Individual considerations such as getting children into the car will also need some thought.

## Motability

If you receive either the Higher Rate Mobility Component of Disability Living Allowance, 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 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

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 give them full details of your needs (height, dimensions, wheelchair type/weight etc.) when you book a vehicle.

### Flying

If you intend to travel by air, 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 helps them to plan for your arrival at your destination.

It is important to take your own cushion with you. This may not be essential for in-flight use but if for example the airline handlers misplace your wheelchair, you will at least have your own pressure relieving cushion to use on a temporary wheelchair provided whilst yours is located. Although it is rare for a wheelchair to be misplaced on a flight, there is a possibility it could be damaged in transit, so 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 (although 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 depending on the airline
- 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 a basic on-board wheelchair)
- Staff to meet you from the plane and help you reach connecting flights or get to the next part of your journey

Once you arrive at the airport, report to the check in desk or seek assistance, even if you have checked in online. It is essential that you have your wheelchair tagged for your destination airport. You will need to plan carefully if you are travelling through a connecting airport on the way to your final destination. If you require your chair at the connecting airport, make sure that it is tagged to go to that airport and then ensure it is tagged again for your final destination.

### **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:

[Holiday guide for Air Travel](#)

[www.direct.gov.uk/en/DisabledPeople/](http://www.direct.gov.uk/en/DisabledPeople/) <https://www.gov.uk/transport-disabled/planes>



## Section 6

- Operations, Appointments and Tests . . . . . 6. 2
- Equipment list . . . . . 6. 3
- My Notes . . . . . 6. 5
- Glossary . . . . . 6. 7



## 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











## Glossary

These pages explain words that we use in your booklet.

Word	Explanation
Ankle - foot orthosis	AFO brace supporting the forefoot and preventing plantar flexion or 'Foot drop'.
Ambulation	A walking motion, often aided by braces and or crutches.
Ankylosis	Loss of mobility in a joint caused not caused by bony deposits of calcium.
Ankylosing spondylosis	A degenerative disease of the spinal column, especially, one leading to fusion and immobilisation of the vertebral bones.
Anoxia	A state of almost no oxygen delivery to a cell, resulting in low energy production and possible death of the cell.
Anticholinergic	A type of drug often prescribed to reduce spasm of smooth muscle, especially, of the bladder.
Anticoagulants	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
ASIA impairment scale	<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>
Ataxia	A problem of muscle co-ordination due not to weakness rigidity spasticity or sensory loss but in-coordination of movement.
Atrophy	The decrease in muscle mass as a result, of a SCI, or a neurological lesion and prolonged immobilisation.
Autonomic Dysreflexia (AD) or (Autonomic hyperreflexia)	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.

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

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



Word	Explanation
Cystoscopy	A direct examination of the bladder using a cystoscope (a small flexible tube) inserted in the urethra.
Decubitus ulcer	A skin sore caused by unrelieved pressure.
Deep Vein Thrombosis (DVT)	Reduced blood flow in the lower extremities after spinal cord injury; can lead to blood clot (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.
Demyelination	The loss of nerve function due to the loss of nerve insulation called myelin. Common in multiple sclerosis and spinal cord injury.
Dermatome	Area of skin that is served by one spinal nerve.
Digital stimulation	A technique for manually or mechanically triggering a bowel movement.
Diuretic	Medicines or substance that cause The kidneys to excrete a larger volume of water from the body. For example, alcohol, coffee, tea, and camomile
DREZ	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
Dura Mater	The tough, outermost membrane surrounding the spinal cord and brain.
Dysphagia	Having trouble eating and swallowing. Requires a speech and language therapy assessment.
Dyssynergia	Failure of muscle co-ordination especially in the bladder.
Electro-ejaculation	A method of obtaining viable sperm from men who are unable to produce a sample by other means; this involves stimulating the seminal vesicure using an electrical probe in the rectum.
Electromyogram (EMG)	An examination that records the electrical stimulation of the muscular contractions and helps determine the origin of a motor deficiency.
Embolism	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.
Excitotoxicity	Excessive release of neurotransmitters, causing damage to nerve and glia cells.
Flaccidity	The absence or decrease in muscle tone.
Functional electrical stimulation (FES)	Application of low-voltage currents to enhance the function of paralysed muscles.

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

Word	Explanation
Hyperbaric Oxygen Therapy	A system of delivering pressurised oxygen to help treat decompression sickness (the bends), smoke inhalation, air embolism and other conditions.
Hyperhidrosis	A condition characterised by abnormally increased sweating or perspiration.
Hypoxia	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.
Incontinence	The involuntary elimination of urine or faeces.
Ileostomy	A surgical procedure that opens the ileum (small intestine) to facilitate removal of faecal material through the abdomen.
Incomplete injury	Generally, a spinal cord injury with preserved sensory or motor function below the lesion level. (ASIA Impairment scale B, C, and D).
Indwelling catheter	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
Ischial	That part of the iliac bone which is located beneath and behind the pelvis, under the buttocks.
Kidney-Ureter-Bladder (KUB) Radiography	Abdominal X-rays of the abdomen to detect abnormalities such as kidney stone, tumours or other obstructions.
Laminectomy	An operation to relieve pressure on the spinal cord.
Laryngotomy	An operation which consist of making an incision in the larynx. It allows intubation to ensure respiration by mechanical means.
Lesion	The site of injury or wound to the spinal cord.
Lower motor neurons	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.
Lumbar	The thickest section of the spine; the lower back below the thoracic area.
Magnetic Resonance Imaging (MRI)	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
Methylprednisolone	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.
Mitrofanoff procedure	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.
Motor neuron	A nerve cell that carries information from the central nervous system to the muscles.
Myelin	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.
Necrosis	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.
Neuron	The main cell of the brain and nervous system.
Neurogenic Bladder	A lack of bladder control due to a brain, spinal cord, or nerve condition.

Word	Explanation
Neuroprosthesis	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.
Occupational therapy	The process 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.
Oedema	An excessive accumulation of fluid in tissue spaces or a body cavity.
Orthosis	An external device that supports the body and limbs or assists motion. For example, glasses, crutches, wheelchair.
Orthostatic hypotension	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.
Osteomyelitis	Infection of underlying bone, often related to decubitus ulcers.
Osteoporosis	Loss of bone material, common after paralysis and inactivity.
Ostomy	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
Paralysis	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.
Paraplegia	Loss of function and paralysis in the legs which translates as a loss of strength.
Percussion	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.
Peripheral Nervous System (PNS)	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.
Peristalsis	Rhythmic muscular contractions of the digestive tract.
Phrenic nerve stimulation	Application of an electrical signal to the phrenic nerve in the neck or the chest, which controls the diaphragm and therefore breathing.
Physical therapy	The process of regaining maximum body function and physical abilities.
Prognosis	Prediction or forecast regarding the course of a disease.



Word	Explanation
Postural hypotension	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.
Pressure sore	A skin breakdown due to unrelieved pressure.
Priapism	An erection that last for several hours or more, a dangerous side effect of certain drugs that improve erectile dysfunction.
Prosthesis	An appliance or device used to replace, a limb, a part of an amputated limb, or an organ that is severely damaged or destroyed.
Quadriplegia	Also known as tetraplegia; paralysis is affecting all four limbs.
Range of motion	Normal movement of a joint, typically restricted by injury.
Reflux	Block flow of a liquid against its normal direction.
Regeneration	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
Rehabilitation	A set of services to restore maximum function; physical, psychological, vocational and social – to a person with a disability.
Reciprocating Gait Orthosis (RGO)	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.
Rhizotomy	The cutting of nerves to interrupt spasticity or pain signals.
Secondary conditions	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.
Secondary injury	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.
Sialorrhea	The term for excessive salivation and drooling.
Shear	The friction on tissues caused by dragging across a surface can cause skin to break down.

Word	Explanation
Spasticity	Uncontrolled muscle activity. This condition can be beneficial for muscle tone but can interfere with everyday activities.
Sphincterotomy	A surgical procedure to relax the urethral sphincter, thus improving bladder function. An alternative is the placement of a stent, which is reversible. Botulinum toxin (Botox A) has also been used to relax the sphincter.
Spina bifida	Congenital spinal cord dysfunction due to malformed neural tube during prenatal development.
Spinal shock	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.
Stoma	(Greek word meaning mouth) A surgically created opening from the skin to the deep viscera (internal organs) for the purpose of collecting the contents.
Stroke	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.
Suprapubic cystoscopy	An opening through the abdomen to drain the bladder with a catheter, known as a 'super tube'.

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

Word	Explanation
Upper Motor Neurons	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.
Ureter	The canal that conducts urine from the kidney to the bladder.
Urethra	The canal that leaves the bladder and ends outside the body which urine passes through to be excreted.
Urinary calculus	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.
Urinary Stenosis	Pathological shrinking of a urinary orifice or canal.
Vertebrae	Each the bones that form the spinal column.

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

We would like to thank and acknowledge the Spinal Injuries Unit at Queen Elizabeth University Hospital Glasgow, for sharing and allowing us to modify their information to help produce this booklet, and to all the patients and relatives who have contributed to this