

Introduction to Spinal Cord Injury Education

The aim of rehabilitation is to promote independence, self-reliance and self-esteem. An important part of the rehabilitation program is education on your spinal cord injury. Participating in an education program will assist you to become either verbally or physically independent.

The program consists of both timetabled and informal sessions. You will receive a patient education pack from the ward nurses, and you will be supported by them to read through this information. If you have any queries please feel free to ask a member of the multi-disciplinary team. The nursing staff and therapy teams will provide informal education throughout your morning personal care routine and in therapy sessions.

It has been our experience that once people leave the London Spinal Cord Injury Centre they realise how important this education program has been.



Now that I have left the cradle of Stanmore I have grown to realise and understand the importance of becoming selfmanaging and that the education was of paramount importance. Yes even at 50 these new skills have empowered me to maintain my independence and to a certain degree recapture some of the "old me" and helped me to focus on my future.



You will also be timetabled to attend a patient discussion group; these are held on a Monday afternoon. The aim of these sessions is to help you learn to understand and monitor your own physical, emotional and spiritual wellbeing. With this knowledge you can avoid complications and increase you independence. Peer Volunteers, all of whom are ex-patients, will attend these sessions and speak with you about their experiences.

As part of rehabilitation we need to monitor the knowledge you have gained from the education program. You may hear staff speaking about a traffic light system.



Red

You have read the education pack, or discussed it with a Nurse.

Amber

You have successfully completed the quiz at the end of each section.

Green

You have successfully completed the refresher and troubleshooting quiz.

We would aim that you are Green on all relevant aspects of education prior to discharge. Should it be possible to go on weekend leave or social outings with family members we would also expect you to be green on the following education topics, Bladder, bowel, skin, medication and Autonomic Dysreflexia (for those with injuries above T6).

If you have any difficulties with your education program please speak to a member of the multi-disciplinary team.





After reading this section you will know:

What the bony spine consists of and the terminology for the different sections		
What the spinal cord does	4 - 7	
What happens to the spinal cord after injury	8	
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Because the spinal cord is such an important part of our nervous system, it is surrounded and protected by the spine. The spine consists of a chain of bony rings called vertebrae which provide support for our whole body, linking head, shoulders, chest and pelvis. It is very strong to support the body weight, supple (discs between the vertebra absorb shock) and flexible to allow turning and bending. Each section of the backbone is given a name and each vertebra is given a number. The areas of the backbone are as follows.

- **CERVICAL** (neck) which has 7 vertebrae.
- THORACIC (chest) which has 12 vertebrae.
- LUMBAR (lower back) which has 5 vertebrae.
- **SACRAL** section which has 5 vertebrae.
- TAIL BONE/COCCYX which has four vertebrae (fused together).





The spinal cord is about as thick as a finger and approximately twenty inches long (50cm). The spinal cord attaches to the brain at the base of the skull and runs almost the length of the back inside the backbone It is a part of your nervous system, made up of bundles of nerve fibres carrying messages from the brain to all parts of the body.

There are three kinds of messages or signals which travel along the spinal cord:

- Sensory (feeling)
- Motor (movement)
- Reflexes

Sensory Messages

Sensory messages are sent along nerve pathways from the body to the spinal cord and then to the brain. When the signal reaches the brain, feeling occurs. This happens so quickly you are not aware of it. There are many kinds of sensory messages. These include the feelings of hot, cold, touch, pain, and pressure. Another sensory message is body position. This message tells you if you are sitting, standing, or lying and where your body parts are in relation to your body.

Motor Messages

Motor or movement messages begin in the brain, travel through the spinal cord, then out the spinal nerves to the rest of the body. These signals tell the muscles in your arms, hands, fingers, legs, toes, chest and other parts of your body how and when to move. Again, this happens so quickly you are not aware of it.

Reflex Messages

A reflex is a movement of a muscle caused by some signal that does not come from the brain. Some body signals only need to reach the spinal cord. These signals loop through the spinal cord and quickly go back to the part of the body the message came from. This causes the body to react. Reflexes protect your body. Reflex signals occur more quickly than feeling (sensory) or movement (motor) messages. They do not have to reach the brain before the body reacts. There are many kinds of reflexes. Reflexes may cause some bowel and bladder emptying. Spasms are reflex actions.

Spinal Nerves

The spinal nerves carry messages to and from the spinal cord. The nerves leave the spinal cord through openings in the vertebrae (foramen).

Spinal nerves branch off the spinal cord in pairs, one going to each side of the body.

The names and numbers of the spinal nerves correspond to the names and numbers of the vertebrae. Every nerve has a special job for movement and feeling.



What is the Spinal Cord and what does it do?



Injuries to the spinal cord do not usually cut through the cord. However, they do cause damage to the thin, fibrous nerve fibres within the spinal column.

Spinal cord injury due to traumatic accidents may be caused by stretching or pinching of the cord where vertebrae have been displaced, or by direct damage to the cord by fragments of fractured bone. Non-traumatic spinal cord injury can be caused by pressure on the spinal cord from disease (cysts or tumours), or any interruption of local blood supply.

After a spinal cord injury, messages below the level of injury are unable to get past the damage in the spinal cord. This means feeling or sensory messages cannot get to the brain. Feeling will be lost below the level of injury. Motor messages are unable to get past the damage in the spinal cord. This means your brain cannot tell the muscles below the level of injury how and when to move. Bowel, bladder, and sexual control may also change after a spinal cord injury. There may be changes in breathing, temperature control, heart rate, and blood pressure.

The classification of your injury is determined after a series of examinations on you - The "ASIA" or "neurological assessment" (ASIA is the American Spinal Injury Association). Your Injury will be assigned a level and a degree of completeness. Your doctor can give you a copy of your ASIA chart if you want one.

Level of Injury

Your level of injury or neurological level is the lowest level of your body that has normal feeling (sensation) and strength (motor function). All nerve impulses coming and going from parts of your spinal cord below your level of injury will either not work very well or not work at all. Your neurological level may be different from your bony level of injury which refers to which vertebrae have been damaged.

Tetraplegia occurs when there is injury to the spinal cord in the cervical area. This may cause loss of feeling and/or movement in the arms, chest, stomach area and legs. Paraplegia occurs when there is injury to the spinal cord in the thoracic, lumbar, or sacral area. This may cause loss of feeling and/or movement in the chest, stomach area and legs.

Completeness of Injury

The anal sphincter is a critical part of the spinal cord injury examination. Its function is responsible for determining whether or not your injury is complete or incomplete because the nerves to the anus and sphincter muscle come from the very lowest part of the spinal cord. If there is some function of the anus, that implies that at least some nerves are going from the brain all the way to the bottom of the cord.

Complete Injury (AIS A)

With a complete SCI there is no voluntary anal contraction or sensation. There will not usually be feeling or movement below the level of injury. A complete spinal cord injury changes the control of all the functions of the nervous system. Your doctor may also refer to this condition as ASIA Impairment Scale (AIS) A.

Incomplete Injury (AIS B-D)

With an incomplete SCI the spinal cord is able to get some messages to and from your brain below the level of injury. If you have any feeling in parts of your body below the injury, particularly your rectum, your classification will be at least AIS B. If you have some weak movement below the level of your injury or voluntary anal contraction, your classification will be AIS C. If your movement is stronger but still not normal, your AIS classification will be AIS D. Normal strength and sensation is classified as AIS E.

You will meet with your consultant to discuss your specific injury.

All spinal cord injuries are different and what happens with one person does not necessarily happen with another. The nerves in the spinal cord are very delicate and when they are injured they are sometimes not very good at repairing themselves. More detail is included in the research section. At present, there are few things that doctors can do to help the nerves in the spinal cord to repair themselves and therefore, recovery depends on how seriously the spinal cord has been damaged. Your recovery and level of ability will depend on many things such as whether your injury is complete or incomplete, the level of your injury, your age, and other medical conditions you might have.

Complete spinal cord injuries are more severe and the more time that passes after the injury the less chance there is of significant recovery. People with incomplete injuries generally get more recovery than those with complete injuries but it is impossible to know exactly how much recovery there will be or how long it will take to happen. Unfortunately, at present there is no cure for spinal cord injury but there are many doctors and researchers around the world looking for ways to help the nerves to repair and recover.

- The bony spine surrounds and protects the spinal cord and consists of different vertebral bones divided into sections cervical, thoracic, lumbar and sacral.
- The spinal cord carries messages from the brain to all parts of the body. It carries sensory, motor and reflex messages.
- After a spinal cord injury, messages below the level of injury are unable to get past the damage in the spinal cord. This means feeling or sensory messages cannot get to the brain.
- The classification of your injury is determined after a series of examinations on you -The "ASIA" or "neurological assessment" (ASIA is the American Spinal Injury Association). Your Injury will be assigned a level and a degree of completeness.

What is the level of your spinal cord injury?

Do you have a complete or incomplete injury?

Do you have tetraplegia or paraplegia?

Do you have reflexes below your injury?





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What is the Urinary System?

The urinary system includes the kidneys, ureters, bladder, sphincter muscles and urethra. The urinary system removes harmful wastes from the body.



The Kidneys

- There are two kidneys in the body, on either side of the back part of the abdominal cavity and below the rib cage
- As blood flows through the kidneys they filter waste and impurities from blood and combine the waste with water and create urine
- They also help regulate blood pressure.

The Ureters

• Muscular tubes that transport urine from the kidneys to the bladder.

The Bladder

- A muscular organ which stores and empties urine
- Smooth, elastic muscles stretch when full (like a balloon) and contract to empty
- Also contains sensory receptors.

The Sphincters

- There are 2 sphincters in the urinary system. Urinary sphincters are small muscles which stay closed to keep urine in the bladder and open to let urine out of the bladder
- The first sphincter is located at the base of the bladder. The second sphincter is located in the urethra.

The Urethra

- The urethra is a muscular tube leading from the bladder to the outside of the body.
- The urethra transports urine to the outside.
- The sphincter muscle squeezes the urethra closed until you need to go

- The urinary system is controlled by a complicated but coordinated system of signals
- Some parts operate subconsciously
- Nerves carry messages between bladder and brain via spinal cord
- As your bladder fills, you feel the urge to pee
- When you go, your brain tells the sphincter muscle to open and the bladder to contract.

This is what happens in more detail:

The bladder contains a large number of nerves. When the bladder is full of urine, it stretches. The stretching of the bladder pushes on these nerves. This sends a sensory (feeling) message from the bladder through the sacral nerves to the spinal cord.

When the message reaches the spinal cord, part of the message loops through the spinal cord, setting off a reflex. This causes the bladder to squeeze (contract).

The other part of the message goes to the brain. When this message reaches the brain, the urge to urinate is felt. If it is not a good time to urinate, a message is sent from the brain down nerve fibers in the spinal cord, through the sacral nerves, to the bladder and to the sphincter muscle. This message tells the sphincters to stay shut and keep the urine in the bladder. If it is a good time to urinate, a message is sent from the brain down the spinal cord through the sacral nerves to the bladder and to the sphincter. This message tells the sphincter down the spinal cord through the sacral nerves to the bladder and to the sphincter. This message tells the sphincter to relax, open and let urine out. A normal bladder completely empties when urinating.

- Most spinal cord injuries will affect the urinary system in some way
- The kidneys and ureters will continue to work
- Some or all signals to and from the bladder won't get through
- Some or all control of the sphincters will be lost
- The subconscious signals may still operate
- You might have little or no control over when you go
- Injuries above T10 usually cause a reflex bladder
- Injuries between T10 and L2 may result in either reflex or non-reflex functioning of the bladder
- Injuries at L2 and below usually cause a non reflex bladder ("flaccid bladder").

During spinal shock, the bladder will not reflex. Spinal shock leaves the bladder limp and unable to empty. When the spinal cord recovers from spinal shock, the bladder will be either a reflex or a non-reflex bladder. Your bladder may be non-reflex after spinal shock and change several weeks or months later to a reflex.

This is what happens in more detail:

Reflex Bladder

After a spinal injury, the bladder will no longer work as it did before the injury. If the injury is above T12, the bladder may empty by reflex. With a reflex bladder, messages from a full bladder are not able to reach the brain, but they do reach the spinal cord. The bladder fills with urine. The bladder stretches. The stretching of the bladder pushes on these nerves. This sends a message from the bladder through the sacral nerves to the spinal cord. When the message reaches the spinal cord, it loops through the spinal cord, setting off a reflex. The message then goes back down the spinal cord through the sacral nerves to the bladder, the bladder and sphincter muscles. When the message reaches the spinal cord through the shadder squeezes or contracts. When the message reaches the sphincter muscle, it will open and let urine out. This reflex will happen when the bladder gets full and stretches.

Remember, messages can no longer get to and from the brain past the spinal cord injury. This means the sensory message from the bladder cannot get to the brain. The urge to empty the bladder will not be felt. Reflexes can occur because these messages do not need to get to the brain. They only need to get to the spinal cord. The bladder management for a reflex bladder is usually a combination of SIC's and medication.

The Non-Reflex Bladder

If the spinal cord injury occurs at L2 and below, the bladder probably will not have the reflex action to empty. Because the spinal cord ends around L1, signals from a full bladder cannot get to the spinal cord. The bladder fills with urine. The bladder stretches. As the bladder stretches, it pushes on the nerves in the bladder. A message will be sent from the bladder through the sacral nerves. The signal cannot get to the spinal cord because of the injury to the nerves leading to the spinal cord. No reflex occurs, the bladder will not squeeze and the sphincter will not open and let urine out. The sphincter may get weak and waste over time increasing risk of leaking. The bladder management for a non-reflex bladder will usually be SI.C.'s done every four to six hours. Injuries between T10 and L2 may result in either reflex or non-reflex functioning of the bladder.

- Urine culture and sensitivity. Test to identify urine infection and type of antibiotic to be used
- **Ultrasound.** Performed in the X-ray department. It gives an Image of the kidneys, ureters and bladder by sound waves, which make up a picture
- **Cystoscopy.** An operation, which is performed if there are problems identified within the bladder e.g. stones. A hard catheter is inserted into the bladder via the urethra. The special catheter has a small camera on the end, which allows the bladder to be seen from the outside
- **Flow rates.** The patient must be able to pass urine onto a designed toilet, which then measures the flow of pressure
- **Urodynamics.** This is a test to evaluate bladder and sphincter function. It shows how much urine the bladder holds and how much urine will cause the bladder to reflex. It shows if the sphincter is working with the bladder as it should
- **Follow ups.** A follow up appointment by the urologist will take place every year or as necessary if your bladder activity changes



The aim of bladder care is to empty your bladder, prevent incontinence, maintain kidney health, reduce risk of UTIs and bladder stones and to maintain independent lifestyle.

There are many ways of managing your bladder. More information on bladder management options can be found in the SIA moving forward DVD.

ISC: Intermittent Self Catheterisation (SIC, ISC or CIC)



- Single use, sterile, disposable catheters.
- Inserted into the bladder through urethra
- One of the safest ways of bladder emptying.
- Provides regular, complete bladder emptying.
- Large range available with different features.
- Requires some hand function

Indwelling catheter



- Inserted into the bladder through urethra
- Can be left inside your bladder for weeks
- Connects to leg or night bag
- Can be used with a catheter valve
- Long term use can lead to:
 - More UTIs
 - Bladder stones
 - A lower bladder capacity
 - Injury to your urethra

Suprapubic catheter



- Inserted through the abdomen into the bladder, an alternative to an indwelling catheter. Connects to a leg or night bag.
- Can be used with a catheter valve, completely reversible
- Still poses a risk of UTIs and bladder stones
- Can block which will require urgent attention to change, usually by your district nurse. Some people will insert a urethral catheter to drain urine if there is going to be a delay in changing the spc.

Managing your Bladder

Penile Sheath (condom drainage, Conveen)



- Like a condom with a funnel at the end.
- Sticks to the penis with an adhesive.
- Can remain in place for 24 hours.
- Can be connected to a leg bag.
- Protects against leakages.
- Wide range of sizes, styles and adhesives.
- You may still have to catheterise to fully empty your bladder.

Managing your Bladder

Catheterising aids

Leg separators and mirrors



Handling aids



Oxybutynin XL	Tablet	10-30mg	Neurogenic bladder instability Prevents bladder spasm	 Dry mouth Constipation Blurred vision Nausea Flushing Urinary retention Headache Dizziness
Tolterodine XL	Tablet	4-8mg	Reduce symptoms of urgency and urge incontinence and increases bladed capacity	 Dry mouth Constipation Flatulence Blurred vision Dry eyes Headache Diarrhoea
Solifenacin	Tablet	5-10mg	Urinary frequency and urge incontinence	 Nausea Vomiting Constipation Diarrhoea Abdominal pain Dry mouth
Tamsulosin	Tablet	Up to 400mcg	Reduce obstruction to urine flow	Low blood pressureDizziness
Alfuzosin	Tablet	Up to 10mg	Reduce obstruction to urine flow	Low blood pressureDizziness

Because your bladder no longer works the way it did before your spinal cord injury, urinary tract infections are common. Germs will be in your urine most of the time but they may not require treatment.

You may have an infection if you have:

- A high temperature
- Blood in your urine
- Leaking of urine between I.C.'s if you usually don't leak
- Burning pain when urinating and feeling like you have to urinate all the time
- Sediment or offensive smelling urine
- Autonomic Dysreflexia of unknown cause or an increase in spasms.

How to reduce the risk of developing UTI's:

- Keep catheter, supplies and leg bag clean.
- Do I.C.s on time and correctly.
- Wash hands before emptying the bladder.
- Drink 6 to 8 glasses of water or cranberry juice a day and eat a healthy diet.
- In hot weather or if you have sedimented or concentrated urine you may need to drink more.

What to do if you are concerned you have a UTI:

- Call the district nurse or doctor to arrange for getting your urine tested and to report your temperature.
- When getting a urine sample tested, it must be fresh. The sample must be collected with sterile equipment.

- Drink at least 6 to 8 glasses of water or cranberry juice a day and stop drinking fizzy drinks. You should drink more fluids than you usually do.
- Take all the medicine prescribed by the doctor to make sure the infection is gone.
- It is best to avoid antibiotics unless you have symptoms or there is definite evidence, from the lab test, of infection.

- The urinary system includes the kidneys, ureters, bladder, sphincter muscles and urethra.
- Before a spinal cord injury, as the bladder fills, you feel the urge to pee. When you go, your brain tells the sphincter muscle to open and the bladder to contract.
- Most spinal cord injuries will affect the urinary system in some way. The kidneys and ureters will continue to work but some or all signals to and from the bladder won't get through. You might have little or no control over when you go. Injuries above T10 usually cause a reflex bladder, Injuries between T10 and L2 may result in either reflex or non-reflex functioning of the bladder and Injuries at L2 and below usually cause a non-reflex bladder.
- Doctors may arrange ultrasound scans, flow rates, urodynamics or cystoscopies to investigate your bladder.
- There are many different ways of managing your bladder, usually intermittent catheterisation or suprapubic catheters to help empty your bladder and medications to control any overactivity in the bladder.
- Urinary tract infections are common. Germs will be in your urine most of the time but they may not require treatment. Signs of an infection requiring treatment may be high temperature, blood in your urine, leaking of urine, burning pain when urinating, offensive smelling or discoloured urine and feeling like you have to urinate all the time. If you are concerned call the doctor to arrange a urine test.

Recap Questions

Do I have a reflex or non- reflex bladder?

What medications do I take for my bladder and what do they do?

How will I know if I have a UTI?

What will I do if I think I have a UTI?

Do I need any investigations?

Notes



Managing your bowel routine

The parts of the digestive system			
What happens after spinal cord injury			
The difference between Reflex and Non-Reflex bowel			
Methods for emptying the bowel			
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The Parts of the Digestive System



An injury to the spinal cord means that nerve impulses located in the bowel are not able to reach the brain, meaning that the message that tells you the bowel is full and it's time to go to the toilet is blocked. It is the sacral nerves that connect the bowel to the spinal cord. Depending on the level of injury this can have different impacts on the functioning of the bowel, and whether the pathway between the spinal cord and bowel (via the sacral nerve) remains intact. A complete spinal cord injury will result in loss of sensation of the need to defeacate and no more voluntary control from the brain. Incomplete SCI will not easily be categorised and should be assessed on an individual basis.
Reflex or Non-Reflex Bowel



If the injury is above T12 then the bowel can empty by reflex- know as a Reflex Bowel. With this type of bowel signals about a full rectum are not able to reach the brain, but can reach the spinal cord. As the rectum gets full and stretches the bowel sends out signals via the sacral nerve to the spinal cord. Once the signal reaches the cord it loops back to the bowel, stimulating contractions and to the sphincter- stimulating the muscles around the anus to relax, open and let stool pass through.

The spinal cord comes to an end at around the L1 level, so if your injury is at T12 or below then signals will stop before reaching the spinal cord. No reflex contraction of the bowel muscles/ relaxing of the sphincter will occur to allow stool to pass naturally- this is called a Non-Reflex Bowel ("flaccid bowel"). Reflex bowel emptying techniques are designed to initiate the bowel's own natural reflex. **Digital Stimulation** is the primary method used to stimulate movement. By inserting a finger into the rectum and moving it around in a circle, the sphincter muscle opens and the bowel muscles squeeze to push stool out. This is best done at the same time everyday to establish a regular schedule for bowel emptying, adjusting frequency to individual need.

Suppositories offer another alternative to stimulate bowel movement, when the person has sensation around the rectal area or digital stimulation does not empty the bowel. There are 2 common types of suppository- glycerine and bisacodyl. These should be administered 30 minutes before planned evacuation and done at the same time every day to train the bowel.

In a non-reflex, or flaccid bowel the natural reflexes can no longer be stimulating- so removing stool is done through Digital removal "**Manual Evacuation**", where a gloved finger is inserted into the rectum and contents are gently removed digitally. Laxatives can be used in a controlled fashion to help move the stool through the bowel into the rectum.

Trans-anal irrigation of the bowel can be defined as a process of facilitating evacuation of faeces from the rectum and descending colon, by passing water into the bowel via the anus in a quantity sufficient to reach beyond the rectum. Transanal irrigation involves the introduction of water into the rectum, using a pumped or gravity fed system via a rectal catheter with an integral balloon Peristeen or via a coneshaped device Qufora. Speak to your nurses or doctor if you want more information on this.

Further interventions are possible. Please discuss with your doctor if you want to know more.

Various other factors affect the workings of both types of bowel and need to be considered if a regular bowel movement schedule is to be established.

Exercise is an essential part of maintaining bone density and muscle tone post injury, but it can also work abdominal muscles and promote peristalsis in the gut.

Abdominal Massage is another way to help stool move through the colon by encouraging peristalsis. By rubbing a hand firmly over your stomach from left to right you can stimulate the movement of the faeces along the transverse colon, through the descending colon and into the rectum. Ask your nurse to show you the best way to do this.

Gastrocollic Reflex is stimulated by a hot drink or by eating a warm meal. Waves of peristalsis in the bowel are initiated within 30 - 40 minutes of eating or drinking a hot drink, and this technique can be timed to coincide with scheduled bowel management.

Diet plays an important part in maintaining healthy bowels. A balanced diet, including one that contains enough fibre, is needed to encourage peristalsis in the gut. About 15 gm of fibre a day is recommended, as the bowel of a spinal injury patient does not respond well to too much fibre. Adequate fluid intake will also help to prevent constipation- if the body is well hydrated it will prevent too much absorption of water by the colon, which can result in hard, dry faeces. Avoiding foods that aggravate the bowel, such as high amounts spice or too much alcohol, will also help normalise a routine.

Meals should be taken at regular times throughout the day, and keeping a **Food Diary** can help to keep intake regular, monitor whether you are getting enough fibre, and see if certain types of food disagree with your bowel. Certain medications can also affect your bowel; consult your doctor if you experience diarrhoea or constipation as a result of starting new drugs.

Various disruptions can occur to a bowel routine if it is not done right or on time. **Constipation** results from too much water being absorbed from the stool in the large intestine, making the stool hard and difficult to pass. This can result from not enough fibre in the diet causing stool to pass through the colon too slowly, not being properly hydrated, not exercising, altering time or composition of bowel routine. Constipation can lead to dysreflexia in persons with a spinal cord injury at T6 and above. In order to prevent it eat more fibre, use a stool softener if needed, drink water every day, do your bowel program on time and do it correctly, exercise as much as possible, drink a hot drink 30 minutes before your program.

An **Impaction** is hard stool stuck in the bowel. This is the result of untreated constipation. No stool is produced during bowel programs for more than 2 days, leaving an uncomfortable bloated abdomen. Laxatives and special enemas are used to move the blockage, and the hard stool can then be manually evacuated.

Diarrhoea occurs when the large intestine does not absorb enough water from the stool, usually because the waste has moved too quickly through the bowel. Some aggravating foods, illness, medicines, using too many laxatives, drinking too much alcohol are among possible causes. The Diarrhoea must be allowed to pass, avoid eating anything or taking any medications that may aggravate it, and suspend your bowel routine until it has stopped for 24 hours.

What are the primary functions of the small and large intestine?

How has the spinal cord injury affected your urge to defecate and why?

How is the functioning of your bowel dependent on your level of injury?

What are the main management techniques for emptying your bowel?

What other techniques can be employed to help achieve a regular bowel routine?

Give some of the main causes of complications with a bowel program and how they can be avoided.

What benefits can we expect from achieving a regular and efficient bowel routine?



	Breakfast	Lunch	Dinner	Snacks
Monday				
Starch cereals, bread, pasta				
Vegetables, fruits				
Milk, dairy				
Meat, fish, seafood				
Tuesday				
Starch cereals, bread, pasta				
Vegetables, fruits				
Milk, dairy				
Meat, fish, seafood				
Wednesday				
Starch cereals, bread, pasta				
Vegetables, fruits				
Milk. dairy				
Meat, fish, seafood				
Thursday				
Starch cereals, bread, pasta				
Vegetables fruits				
Milk dairy				
Meat fish seafood				
Friday				
Starch cereals, bread, pasta				
Vegetables fruits				
Milk dairy				
Meat Fish seafood				
Saturday				
Starch cereals, bread, pasta				
Vegetables fruits				
Milk dairy				
Meat fish seafood				
 Sunday				
Starch cereals bread pasta				
Vegetables fruits				
Milk dainy				
Most fish sosfood				

Result of bowel Care





Name the parts of the skin	3
Describe how the skin works before and after a spinal cord injury	4 - 5
Describe a skin sore	6
Name the vulnerable areas	7
List the causes, signs, treatment and prevention of skin sores	8
Recap questions	9

Functions of the Skin

- Protection
 - Internal organs Acts as barrier against infection
- Sensation
 - Touch, pain, Pressure
- Internal Physiology
 - Excretion of waste products ie sweating
 - Maintaining body temperature ie pilo-erection, sweating to cool or warm body.

Layers of the Skin

- Epidermis Protects the deeper skin layers against injury and dehydration
- **Dermis** Part of skin where many functions take place •
- **Subcutaneous Layer** Acts to insulate body and as cushioning agent. •

The Dermis

- Blood Vessels Carry oxygen & nutrients to skin and tissue
- Nerve Endings Transport messages to the brain i.e. touch, temp and pain
- Sweat Glands Produce sweat to cool down when hot •
- Sebaceous Glands Produce oily substance to keep skin soft and water proof
- Hair Follicle Hair used for temperature control



After a spinal cord injury, the skin will still protect the body. It will also provide a barrier against infections. But there are changes in some of the other functions.

Loss of Feeling or Sensation

If there is no feeling below the injury level, no warning signals will tell you when you have hurt yourself. For example, you will not feel a bruise, cut or burn below the level of your injury.

Decreased Body Movement

Before a spinal cord injury, feelings of pressure, pain and discomfort caused you to move often and change your body position. After spinal cord injury, messages or signals are not able to get to the brain to tell you when to move. Sitting or lying too long cuts off the blood flow in the skin. Blood flow to the skin keeps it alive and healthy. If the skin does not get blood, it will die. Lack of movement and exercise below the injury level decreases blood flow to those areas. This is why it is important to be active after spinal cord injury.

Changes in Body Temperature Control

With a complete spinal cord injury, you will not sweat or shiver below the level of injury. Loss of sweating below the level of injury can cause the skin to become dry, flaky and sometimes crack.

What Is A Skin Sore (Pressure ulcer)?

The most common cause of a skin sore is pressure. Sitting or lying in one position too long will cause a skin sore. Certain areas of the body get more pressure than others. These areas are located over bony places such as the hip, heels and sacrum. The skin over these bony areas is squeezed between the bone and other surfaces such as a bed, a chair or clothing. When the skin cannot get the needed blood, the skin cells begin to die. This is the beginning of a pressure sore.

One of the first signs of a possible pressure sore is a change in the color of the skin. The area will become pink or red, warm and firm. Persons with dark skin will notice a darkened or shiny area. The area around the early skin sore also changes. It may also feel warm and firm. This is the first stage of a skin sore. The skin is unbroken on the

outside. In the first stage, the skin heals quickly if the right steps are taken to relieve pressure.

If the pressure is not relieved, it will get worse. The skin will become red, purple or black.

Swelling will continue. A blister may be seen. At this point, the dermis (the bottom layer of the skin) is involved.

The skin often becomes open and infected. Treatment at this stage may involve weeks or even months of bed rest staying off the area. If the sore is deep into the muscle or bone, surgery may be needed to clean out the infection and close the sore.

Once you have had a pressure sore, the skin will never be as strong as before. This means it is even more likely to break down again.

The most Vulnerable Areas are:

- Occiput (back of head)
- Ears
- Shoulder Blades
- Elbows
- Natal Cleft
- Gluteal Folds
- Sacrum
- Ischium (Sitting Bones)
- Groin
- Foot (bony areas like the ankle and heels)
- Hips







Pressure

Pressure is the biggest cause of skin breakdown and skin sores. Pressure over bony areas is most likely to cause break-down because blood flow is cut off to the skin.

Some **DANGERS** are:

- Clothing and Footwear
- Oedema/Swelling
- Seating Cushion
- Braces/Splints
- Positioning/mattress

Friction/Shearing Forces

Most commonly occurs when transferring or moving around. The top layer of skin is damaged by the dangers listed below which makes this area of skin more vulnerable to pressure.

Some **DANGERS** are:

- Dragging
- Scraping
- Spasms

Local Trauma

This means damage to the skin, such as:

- Abrasions
- Bruises
- Pimples / Spots
- Burns or Moisture of any kind

Monitoring Skin Condition

Remember, because of the injury to the spinal cord, the nerves in your skin cannot send a message to the brain to let you know when your skin is in trouble. For this reason, daily inspection of your skin is a very important part of your skin program. By looking at your skin every day, problems will be caught before they become serious. Checking your skin is your responsibility! You should check your whole body at least twice a day, paying special attention to bony areas. This is done every morning when you dress and every evening when you undress. If you do not get out of bed, you should still check it in the morning and again in the evening. If you have an accident (burn, cut, bruise), check your skin as soon as possible. Remember to check skin problem areas more than twice a day.

Your Skin Care Program

A good skin program will keep you from getting skin sores.

Prevention is the Key!

Your skin program should include:

- Scheduled pressure relief when you are sitting for two consecutive minutes every hour
- Skin checks at least twice a day in the morning before you get out of bed, and in the evening soon after you get back into bed
- A turn schedule when you are in bed
- Early treatment of all skin problems
- Wearing the right shoes and maintaining good foot-care. Shoes will need to be at least a size bigger due to possible swelling of your feet
- Wearing the right clothing. Wear clothes that allow the air to circulate and are not too tight
- Safe transfers
- Avoiding heat sources that may burn your skin
- Checking your wheelchair cushion for wear and tear
- Sitting in the chair correctly.

The skin is the body's largest organ and is responsible for protecting you from things like infections. The skin also helps to control body temperature and allows you to feel things like pain, touch, pressure, temperature and body position.

With injury to the spinal cord, there will be some changes in the ability of the skin to protect the body. Two important changes are loss of feeling below the injury and loss of temperature regulation.

Because of the loss of feeling and movement, you will need to learn how to protect your skin from problems like pressure sores, burns, bumps and bruises. Care must be taken to prevent overheating and from being too cold. The skin care program that you learned at LSCIC will help you avoid problems, but you must take care of your skin every day.

Important key points to remember about your skin care program:

- Do pressure relief every hour for two minutes
- Take care of your wheelchair cushion
- Inspect your skin every morning and every night
- Know what you are looking for when checking your skin (red areas, bumps, bruises, dark spots, warm, hard places, scratches, cuts, pimples and rashes)
- Know what to do for each type of skin problem

Rule 1: always stay off the problem area

- Stick to your turn schedule at night
- Keep your skin clean
- Exercise, eat a healthy diet, drink 6 to 8 glasses of water a day and get plenty of rest
- Wear clothing that allows air to circulate
- Do not cut off blood flow with too tight clothes, stockings, belts or shoes
- Perform good foot care.

Most importantly, take care of problems early before they become serious. If you are not sure what to do for a skin problem, do not wait. Call your doctor.

Recap Questions

Being sure that skin checks are done and making decisions regarding skin care is the responsibility of?

The most important thing to do if you discover a red or dark spot caused by pressure is to?

List 5 extremely vulnerable areas of skin breakdown.

When checking your skin, as well as looking at it in a mirror, what else should you do?

What are 3 main factors which contribute to skin breakdown?

How often should you perform/request pressure relief when sitting in your wheelchair?

Notes

Notes



Autonomic Dysreflexia (AD) Hypotension & Temperature Control

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Autonomic Dysreflexia (AD) is a life-threatening event that must be treated immediately.

Autonomic Dysreflexia is a serious condition. It is a reaction of the body caused by nerve signals trying to get to the brain. A spinal cord injury blocks the signals trying to get to the brain. This condition can happen if your spinal cord injury is T6 or above. When your bladder, bowels or skin are in trouble, they send signals to your spinal cord and a reflex begins. This reflex causes the blood vessels below your injury level to tighten. This makes it harder for the blood to pump through the blood vessels and causes the blood pressure to rise.

Your brain tries to send a message to the blood vessels to open up. These messages cannot get past the spinal cord injury. Therefore, your blood pressure keeps rising. A very high uncontrolled blood pressure can cause a stroke, heart attack or death. The blood vessels above your injury level open up and get larger to try to balance what is happening below the level of injury.



What causes AD



Causes:

- Your bladder or bowel when they are too full
- Bowel program when done too long or too hard
- Pressure on your skin
- Pressure sores
- Ingrown toenails
- Bladder infections
- Sexual or reproductive activity
- Other medical causes: stomach ulcers, heart attack, asthmatic episodes, lung infections, and blood clots in your legs.

How to tell when you have dysreflexia:

- A severe pounding headache that gets worse
- High blood pressure. You should know your normal blood pressure. Usually there is a 20 to 40mmHg rise in blood pressure above your normal level but it may be much higher.

My normal blood pressure is: _____

- Red blotches above the level of injury (face, neck, arms)
- Sweating above the level of injury
- Goose bumps above the level of injury
- Stuffy nose.

What to do if you have dysreflexia:

- Sit up if you are not already doing so (this helps to lower your blood pressure).
- Remove or loosen tight clothing, such as your binder, TED stockings, socks and shoes.
- Do an intermittent catheter. If you have a urethral or suprapubic catheter, check tubing for kinks. Change the catheter if the urine passage is blocked. If you use a convene, be sure the convene or strap is not too tight.
- Do your bowel program. You may need to insert a numbing ointment like Instilagell. If doing a bowel programme causes dysreflexia: stop the bowel programme
- Check your skin. Check for something that may be irritating your skin. This may include sharp or hard objects, hot or cold objects, tight clothes or shoes.

If signs of dysreflexia continue or get worse call for emergency assistance. If dysreflexia will not go away, and your blood pressure remains very high, medication will have to be given to lower the blood pressure, usually Nifedipine 10mg capsules which can be bitten or pierced and the contents squirted under the tongue.

BE ASSERTIVE! Emergency room staff are not always aware of the special needs of people with spinal cord injuries. Give them your AD card and ask them to check your blood pressure immediately.

How to prevent dysreflexia:

- Empty your bladder on schedule.
- Empty your bowel on schedule.
- Stay free of bladder infections.
- Know the signs of a bladder infection and notify your doctor if they occur.
- Stay free of constipation or impactions.
- Prevent skin sores.
- Do good foot care and clip toenails straight across to prevent ingrown toenails.

Autonomic Dysreflexia Recap Questions

Are you at risk of AD?

What are the symptoms of AD?

What are the causes of AD?

How do you manage AD?

How do you avoid AD?

Hypotension

What is it?

Hypotension is a decrease in blood pressure that happens when you sit up or stand up too quickly. When you get up quickly, gravity causes the blood to rush down to your legs. Since your leg muscles don't work the same as they used to, blood will not be pumped quickly enough up against gravity to the heart and the head. This causes a quick drop in blood pressure. This drop in blood pressure can make you dizzy, lightheaded and even faint.



Symptoms:

- Light-headedness
- Seeing Stars
- Nausea
- Ringing in the ears
- Fainting
- Numbness of the face

- Gradually come to a sitting or standing position
- When you are going from a lying down to a sitting position, raise the head of the bed for about 15-20 min before getting up
- When you are about to stand, first dangle your legs over the bed for a few minutes
- Wear an abdominal binder
- Wear elastic stockings (knee or thigh height)
- Drink plenty of fluids
- Salt tablets may help you to retain water and increase your blood pressure. Ask your doctor if this is appropriate for you.

Will I have to deal with this forever?

- Often this condition goes away within a few weeks or months once your body has had time to get used to being upright again
- A gradual standing program on the tilt table or standing frame can help recovery. Your physiotherapist will help develop a program with you if this is appropriate
- Some people will always have low blood pressure. They will have to take this into consideration when sitting or standing up. They may have to gradually get upright and/or utilize a tilt feature in a power wheelchair.

Body temperature is controlled by a heat regulation centre in the brain. If your spinal cord injury is T6 or above, you may have changes in temperature control. This is because after a spinal cord injury, messages about being hot or cold cannot get past the spinal cord injury to reach the brain. Before injury to the spinal cord, when you were cold, your body would shiver to warm you. When you were too hot, your body would sweat to cool you. This process kept your body temperature normal.

When messages about being hot or cold cannot reach your brain because of your spinal cord injury, you will not sweat or shiver below the point of injury. This makes it hard for your body to control its temperature. As a result, your body may get too hot or too cold. Poikilothermia is a term used to describe the fact that SCI affects a person's ability to control their body temperature. Instead, the paralysed body adopts the temperature of the local environment.

Causes:

- Staying in the sun or outside on a hot day for too long
- Using too many blankets
- Using a pool, bath, shower or hot tub that is too warm.

How to tell if your body is overheating:

- You may feel: very tired or weak, dizzy, faint, thirsty
- You may have: headache, cramps, upset stomach, flushed face, elevated temperature

What to do if your body is overheated:

- Drink plenty of cool liquids (especially water)
- Sponge or mist your body with cool water
- Remove any heavy or dark clothing
- Stay in a cool place, near a fan
- Take your temperature. If it is higher than 38° C, call the doctor.



How to prevent your body temperature from becoming too high:

- Avoid being in direct sun or very hot weather for more than 15 to 20 minutes at a time
- Stay in a cool or shady spot if you stay outside a long time
- Spray your body with cool mist from a water spray bottle
- Wear sunscreen to avoid sunburn
- Drink plenty of water when out in the heat
- Wear a hat or sun visor
- Wear light colored, loose fitting clothing. Cotton fabrics will let air circulate
- Avoid very active exercise in hot weather.

Lowered Body Temperature

Causes:

- Not dressing warmly enough in the cold
- Staying in the cold too long

How to tell if your body is too cold:

- Shivering above the level of injury
- Pale or white hands, fingers, toes, lips and face
- Take your temperature. If it is below 36.0° C you are getting too cold

What to do if your body is too cold:

- Drink warm liquids like coffee, tea, and hot chocolate
- Cover up with warm blankets
- Move to a warm place. Remember, do not get your hands or feet too close to a space heater or fire; you may burn areas of skin
- Dress in layers
- Keep skin dry.

How to prevent your body temperature from becoming too low:

- Avoid being in cold temperatures for long periods of time
- Check your skin for frostbite every hour if outside for a long time
- Wear a sweater, coat, hat, and gloves when out in cold weather
- Dress in layers
- Do not drink beverages with alcohol because alcohol will make you feel warmer than you are.



Recap Questions

What are the symptoms of hypotension?

How do you manage hypotension?

How can you help to avoid hypotension?

How can you tell if you are overheating?

How do you manage overheating?

Recap Questions

How can you try to avoid overheating?

How can you tell if you are too cold?

How do you manage being too cold?

How can you try to avoid becoming too cold?



Nutrition

After reading this section you will know:

Nutrition	3
Diet and its implications	4
Weight management	5 - 6
Eating a healthy variety of foods is the key to good nutrition	7 - 9
Recap	10
After a spinal cord injury, your body's systems, such as bowel, bladder and skin function, are altered due to your paralysis. Basic good nutrition is important for everyone. The foods you eat affect how you look, how you feel and how your body systems work.

A good diet helps to:

- Maintain energy levels
- Fight infections
- Maintain body weight
- Keep all your body systems working properly



Bowel management:

Individuals with spinal cord injury may have a 'neurogenic' bowel. This means that messages from the brain that control the downward muscular movements of the bowel are either absent or not working properly. This makes it difficult for waste to move through the intestines.

You could try:

- Eating a diet with plenty of fibre
- Drinking plenty of fluids in between meals
- Drinking some warm fluids, tea, coffee or water early in the morning before breakfast
- Having a glass of prune juice (this can be mixed with apple juice to improve the taste).



Skin:

Pressure sores are always a concern to individuals with spinal cord injury. Your skin is more likely to breakdown when you do not eat healthy meals and snacks. If you should develop a pressure sore a diet high in protein, vitamins and minerals is recommended to assist healing.

Bladder:

Individuals with spinal cord injury may be more prone to developing Urinary Tract Infections (UTI). A high fluid intake reduces the likelihood of UTI's.

If on self-intermittent catheterisation (SIC's)

x 4 a day - 2 litres/day x 5 a day - 2.5 litres/day

If an indwelling or supra-pubic catheter in-situ

2.5-3 litres / day

Overweight:

One of the biggest problems for people with spinal cord injury is weight gain. A sedentary lifestyle due to paralysis makes it easy to gain weight and very difficult to lose. This weight gain will affect mobility by putting extra stress on shoulder joints and making it harder to push your wheelchair. It will also be more difficult to transfer and may affect your independence.

- You will not be able to eat as much as you did before your spinal cord injury without gaining weight
- Stay as active as possible. Engage in different activities or use modifications or adapted equipment. Any exercise is helpful
- Eat regular meals. Feeding your body throughout the day will help you control your appetite, and you'll actually eat less than if you skip meals
- Watch portion sizes. Read labels to see what a portion size actually is
- Eat a variety of foods. Try to eat something from each of the food groups (meat/protein, milk, fruits, vegetables, and grains) at each meal.



An example plate if you are trying to lose weight

You will notice half the plate is made up of vegetables, a quarter with protein (e.g chicken) and a quarter with a starchy Carbohydrate (e.g Rice or potatoes).

Underweight:

Being underweight can be just as big of a problem as being overweight. A poor diet can be responsible for weight loss, decreased stamina and strength, thinning of the bones, vitamin deficiencies and skin breakdown from bony protrusions on the hips, buttocks, and sacrum. Adding the following to your diet will help prevent weight loss:

- High calorie milkshakes and snacks can help increase energy.
- Add calories to the foods you already eat e.g by adding creamy sauces, butter/margarine, cream and cheese
- Full fat yoghurts, custards and milky puddings



Eating a healthy variety of foods is the key to good nutrition

7

Your diet should include:

Carbohydrates



- Starchy or 'filler' foods
- Potatoes, rice, pasta, bread
- These are an important source of energy, fibre and vitamins
- Should be included at every meal
- Low in energy...it's what you add to these foods that increases the energy content
- Choose wholegrain varieties for extra fibre.

Fruits and vegetables

- Aim for 5 a day (A portion is 2 large tablespoons of vegetables, 1 small bowl of salad, 1 medium-sized fresh fruit, handful of grapes, or 1 small glass of juice)
- Important source of fibre, vitamins, minerals
- Fresh, frozen, tinned and dried are all suitable
- Choose vegetables tinned in water, with no added salt or sugar, and fruit in natural juices rather than syrup
- Variety is important, aim for a rainbow of different coloured fruit and vegetables.



Milk and Dairy foods

- Aim to have 2-3 portions per day (A portion is a 200ml glass of milk, 1 small pot of yoghurt, or 1 matchbox size piece of cheese-40g)
- Good sources of calcium, protein, vitamins, minerals
- Choose low fat / diet options, minimise hard cheese portions.
- Non-dairy sources of protein (meat, fish, eggs and beans)
- You should have 2-3 portions per day (a portion is a piece of meat the size of a pack of cards, 2 eggs, or 4 teaspoons lentils/ beans cooked)
- Important source of protein, iron and zinc
- Choose:
 - Lean meat
 - Fish especially oily fish
 - Eggs
 - Beans
 - Lentils
 - Nuts
- Limit processed meat such as sausages and salami to once per a week as these are high in fat and salt.

These foods provide energy but may contribute only small amounts of other nutrients. They are not essential to a healthy diet but add extra choice and taste. Many people eat far more from this group than we actually need. A portion is 1 tablespoon of Caesar dressing, 1 teaspoon of butter, 1 teaspoon of oil or 2 teaspoons of low fat spread.

Fibre

- Fibre or 'roughage' is found in foods that come from plants. It is the part of fruits, vegetables and grains that cannot be digested
- Fresh or dried fruits, vegetables, brown or wild rice, dried peas and beans, nuts, wholegrain breads and cereals are a good source of dietary fibre
- High fibre foods can help keep bowel movements regular.

Water and fluids

Water is an important nutrient that most people do not think about when planning their diet:

- It regulates body temperature
- Carries nutrients through the body
- Helps prevent urinary tract infections
- Keeps stools soft for regulating your bowel.

Recap Questions

What does a diet help to do?

What methods can you use to manage your weight?

What is key to good nutrition?

Why is drinking water important?

Notes



The Respiratory System

After reading this section you will:

Understand the purpose of breathing and respiration		
Name the different parts of the respiratory system, including the respiratory muscles	s 4	
Describe how the respiratory system works before and after spinal cord injury	6 - 7	
Know how to maintain a healthy respiratory system; 8 List the causes, signs and symptoms, treatment and prevention of chest infections	3 - 11	
Key points, questions and your baseline observations 12	2 - 14	

The primary function of the respiratory system is to supply the blood with oxygen in order for the blood to deliver oxygen around the body and to remove carbon dioxide (waste product) from the blood stream. Breathing is the process of moving air in and out of the lungs. When the air is in the lungs it fills the alveoli which are tiny little air sacs in the lungs; it is here that the exchange of oxygen into the blood and carbon dioxide out of the blood occurs. Once the oxygen is in the blood stream, it is pumped around the body by the heart via the circulatory system.

The parts of the respiratory system

The respiratory system is made up of the nose, trachea, bronchi, lungs, heart, diaphragm, and the intercostal, abdominal and accessory (neck and shoulder) muscles.



The parts of the respiratory system

The **nose** humidifies, warms and filters the dust and dirt from the air.

The **trachea**, also known as the windpipe, is the tube leading from the throat to the lungs.

The **bronchi** (bronchial tubes) are two branches leading from the trachea to the lungs.

The **heart** pumps blood around the body.

There are two **lungs**, one on each side of the chest. As previously discussed, air is taken into the lungs where the exchange of carbon dioxide and oxygen occurs in the alveoli.

The **diaphragm** is located underneath the ribcage where it separates the chest from the abdomen; it is the main muscle used for inhalation. When it contracts, it flattens and moves downwards increasing the volume of the lungs. Enlarging the lungs creates suction which draws air into them through the nose or mouth.

The **intercostal muscles** assist the diaphragm by expanding (external intercostal) and contracting/depressing (internal intercostal) the rib cage.

The **abdominal muscles** are the muscles that you use to cough and sneeze. When they contract, they push the diaphragm up which forces the air out of the lungs (along with secretions if they are present).

The accessory muscles are located in the neck and shoulders. When breathing becomes difficult, these muscles contract to help the main respiratory muscles to expand the rib cage.

When the diaphragm and intercostal muscles contract, air is sucked in to the lungs through the nose or mouth, it then travels via the trachea to the right and left lungs. The lungs are made up of 600 million little air sacs called alveoli; the air fills the alveoli and the exchange of oxygen into and carbon dioxide out of the bloodstream occurs. The oxygen filled blood is then pumped around the body by the heart. When the diaphragm and intercostal muscles relax, the lungs recoil and push all the carbon dioxide rich air out of your lungs. This process is repeated 12 to 18 times a minute in a healthy adult.



Breathing is controlled by the brain. Special centres within the brain send messages via the spinal cord to the nerves that directly control the muscles of respiration.

Mucus secretions in the respiratory system help protect the lungs by trapping foreign particles that enter it, particularly through the nose during normal breathing. Secretions found in the respiratory tract are often referred to as phlegm. The presence of secretions in the nose, throat and lungs is normal and is usually cleared by blowing the nose or coughing. Following a spinal cord injury it can be more difficult to clear secretions, there may also be increased production of secretions, particularly if a chest infection has developed which can be uncomfortable. It is therefore important that assistance is given to clear secretions for comfort and for the prevention of chest infections. How the respiratory system works after a spinal cord injury. **7**

Changes in respiration occur because the nerve signals that travel from the brain, via the spinal cord to the respiratory muscles are interrupted by the injury to the spinal cord.

The effect of a spinal cord injury on the respiratory system is dependent on the level and location of the injury to the cord. The higher up the cord the injury is, the greater the impact on the respiratory system. The amount of impact the spinal cord injury has on respiration is also dependent on whether the injury is complete or incomplete.

Spinal cord injuries at the T12 level or below will not/are unlikely to have respiratory problems related to their spinal cord injury.

Level of Injury	Muscles Affected	Likely Effect
C1 & C2	Accessory muscles, Intercostal muscles, Diaphragm and abdominals	Will require a ventilator for breathing and manual treatments to clear secretions as unable to cough and clear secretions independently.
C3, C4 & C5	Accessory muscles (partially affected), Intercostal muscles, Diaphragm (partially affected) and abdominals.	May require a ventilator some or all of the time. Will require manual treatments to clear secretions as unable to cough and clear secretions independently.
C6, C7 & C8	Accessory muscles (partially affected), intercostal muscles and abdominals.	Unlikely to require ventilator assistance to breath. Likely to require manual treatments to clear secretions as unable to cough and clear secretions independently.
T1 to T5	Intercostal muscles (partially affected) and abdominals.	Independent breathing. May require manual treatments to clear secretions as unable to cough and clear secretions independently.
T6 to T12	Intercostal muscles (partially affected) and abdominal (partially affected).	Independent breathing. Less likely to require manual treatments to clear secretions but may occasionally need an assisted cough due to weak abdominals.
L1 to S4	No respiratory muscles are affected.	No effect on breathing.

The above table indicates the likely outcome for complete injuries; incomplete injuries may vary from the above.

There are some things that you can do to keep your lungs/respiratory system as healthy as possible.

- Exercise is an important part of maintaining a healthy respiratory system along with the other known benefits of regular exercise. You can speak to your physiotherapist to discuss the best way for you to exercise to maintain good respiratory and cardiovascular health
- If you are at high risk of developing respiratory complications, it may be beneficial for you to complete regular breathing exercises. Your physiotherapist can help you with a breathing exercise programme if it is required
- Be aware of what is normal for you; following spinal cord injury, it is likely that your breathing pattern will change. Knowing what is a normal breathing pattern for you, the number of breaths you take in a minute, what your normal amount of secretions are, what your secretions look like (colour and consistency) will help you to identify if there are any changes. Changes to your normal breathing patterns can indicate that you are developing a chest infection
- Early recognition of the signs of a chest infection means that you are more likely to start the correct treatment quickly. This can reduce the potential severity of the chest infection and the impact that it has on you
- Stop smoking. Smoking tobacco increases the volume of secretions, decreases the activity within the cells of the lungs, causes destruction of the alveoli and increases the likelihood of developing a chest infection. There is also evidence that smoking marijuana can cause narrowing of the airways and inhibition of your immune system which lowers your body's resistance to disease. For help with smoking cessation, follow this link **www.smokefree.nhs.uk**
- Maintaining a healthy weight reduces shortness of breath, reduces the risk of getting chest infections and improves the circulation of blood and transportation of oxygen around your body
- Having annual flu vaccinations will help to boost your immunity against these common infections. You will also require a pneumonia vaccine every five years

Keeping your Lungs Healthy

- Drinking plenty of fluids keeps all the tissues in your body well hydrated. If you get dehydrated, it is likely that your secretions will become thicker and more difficult to clear which increases your risk of developing chest infections
- Eating a well balanced diet can boost your immune system
- Try to stay away from known pollutants such as smoke, dust and dangerous chemicals as well as cold and flu germs from other people around you.

Managing a Chest Infection

Different types of treatment are listed below:

Medication. If you have developed a chest infection, it is likely that you will need antibiotics. The correct type of antibiotic required is usually decided following analysis of a sputum sample. If you have pain associated with your breathing problems, it may also be appropriate for you to take pain killers. You must consult your doctor for advice regarding medication.

Postural drainage. Certain body positions allow gravity to drain secretions from the outer parts of your lungs to the central larger airways which will make them easier to clear by coughing or assisted coughing.

Vibration, percussion & shaking. These techniques loosen secretions from the walls of the lungs so that they become easier to clear. Carers are usually trained in how to carry out these techniques if it is likely that you will need them.

Assisted coughing. An assisted cough is a way of helping a spinal cord injured person to cough and clear secretions from the lungs. The idea is to imitate the muscles that normally help us to cough (your abdominals).

Incentive spirometer. This is a breathing device that helps to exercise your lungs by making you take deep breaths. It can help you to make your breathing muscles stronger.

It is not recommended that you or your carers try any of the above manual techniques without training as there are some circumstances where manual techniques are not advised. Signs that you may be developing a chest infection or that you are not getting enough oxygen into your lungs and what to do:

Signs & Symptoms	Action to Take
Increased effort required to breathe or shortness of breath, this can include taking more breaths per minute.	Increase the number of times you do your breathing exercises. Consult your doctor prior to becoming very fatigued.
Increased secretion production. Secretions may also be yellow or green which indicates the presence of infection (if blood is present in your secretions contact a doctor).	If the secretions have changed colour, obtain a sample in a pot and take it to your doctor so that you can make sure you are given the correct antibiotics if required. In the meantime, increase the frequency of breathing exercises, manual treatments and assisted coughs (as outlined in your carer handbook). Make sure that you keep well hydrated.
A rise in body temperature (usually more then 38°C) can indicate that you have an infection somewhere in your body.	Consult your doctor.
An increased pulse rate (usually over 100 beats per minute) may be a compensatory mechanism when you are not getting enough oxygen.	Consult your doctor.
Subtle changes in your level of consciousness such as restlessness, irritability and confusion should be investigated as to the cause as they can indicate a problem with your respiratory system.	Consult your doctor. If appropriate, ask your carers to assess your chest (they are likely to have been shown how to do this during their training) to see if there are secretions present and increase the frequency of breathing exercises, manual treatments and assisted coughs (as outlined in your carer handbook). Make sure that you keep well hydrated.
Pain when you breathe Early morning fever, headache or unusual drowsiness.	Consult your doctor.
Increased spasms can be a sign of infection somewhere in the body.	Consult your doctor.

If in doubt, call your doctor, NHS Direct on 0845 4647 or the London Spinal Cord Injury Centre on 0208 9095588/5583 for advice. IF IT'S AN EMERGENCY, CALL AN AMBULANCE ON 999.

Sleep Apnoea

Sleep apnoea is a sleep disorder where an individual may experience abnormal pauses in breathing or instances of abnormally low breaths per minute during sleep.

If you experience any of the following symptoms on a regular basis, please contact the spinal cord injury centre for advice:

- Morning headaches
- Not feeling refreshed when you wake up after a night's sleep
- Falling asleep inappropriately in the day
- Irritability

The effect of a spinal cord injury on the respiratory system is dependent on the level/location of the injury to the cord and whether your injury is complete or incomplete.

There are lots of things that you can do to maintain a healthy respiratory system and reduce the risk of developing chest infections.

If the alveoli in the lungs become clogged with secretions, not enough oxygen will get into the lungs and into the blood stream to be circulated around the body.

Early recognition of the signs of a chest infection is important; in order to recognise changes quickly, it is important to know what is normal for you (your baseline observations) so that you can tell when something is different or unusual.

What you have learned about the respiratory system

What parts of your respiratory system are affected by your spinal cord injury?

List four ways that you can keep your lungs healthy.

Name three different signs and symptoms that you may be developing a chest infection.

What would you do if you were experiencing the above signs and symptoms of a chest infection?

My baseline observations

Resting heart rate (beats per minute)	
Resting respiratory rate (breaths per minute)	
Normal temperature	
Normal blood pressure	
Breathing pattern (are my breaths rhythmical, does the right and left side of my chest rise and fall equally, is there a pause between breaths etc)	
How much chest treatment do I normally need (hourly, once per day etc)	

Notes



Coping and Independence

After reading this section you will know:

Information from research into how people cope positively with spinal cord injury	
Ideas for your "Coping Toolkit"	4
Information on resources that may help you	4
Suggestions for how you might help other patients	4
Ideas about independence, interdependence and choice	5
How some of our ex-patients define independence, how they challenged traditional concepts	6
Reflecting on what is important for you to take control in your life	6
Recap questions	7

2

In the Stanmore SCIC, there is an ongoing Action Research project, looking at how nurses can best meet the emotional needs of patients. You may be asked to comment on the assessment tool which is being developed (the Stanmore Nursing Assessment of Psychological Status or "SNAPS").

A previous study conducted in 4 units, including ours, looked at the experience of women. A theme of "vulnerability" emerged from the interviews, and ways to contain this were discussed, such as enhancing privacy in wards and bathrooms, and training staff to speak sensitively to patients.

A Swedish study looked at the importance of different elements of the rehabilitation programme, and concluded that client-centred practice was most important, with patients setting their own goals. Another concluded that the vision and calibre of the staff made the most difference to the patient outcomes.

A study conducted in the UK looking at peer support found that informal peer support (the support you receive from other patients in your bay) was highly valued.

A large study pooling results from a UK and a US sample, found that over time, men with SCI reported improved quality of life, and this was accounted for by a shift in their priorities. They moved on from missing the physical activities they previously treasured, to appreciating the activities that were still available, such as spending time with their families.

Findings such as these help give hope to patients and their families, that a good adjustment is common, not the exception. The studies also help us to improve the way we structure the programme and train staff and volunteers. The Psychologists continue to pursue research, and attend conferences, to bring back the benefits of the international spinal injury research community.

There is no single strategy for dealing with all the challenges of SCI. Just as you would not try to prepare a meal with only one utensil, or renovate a house with only one tool, you will need a range of methods to cope with rehabilitation and return to life in the community. Talk to other patients and the Peer Support volunteers, about things or people they have found helpful. For example:

- Being assertive (not aggressive);
- Being able to direct your care or ask for assistance;
- Having ways to relax when you feel angry, stressed, anxious or in pain;
- Planning and delegation skills;
- Knowing where to get good advice and support;
- Making a decision to cope as actively as you can;
- Learning ways to manage negative thoughts and set realistic goals.

Share your ideas with your relatives and listen to their ideas. Remind each other what has helped, when the going is tough and you/they cannot recall past successes.

Resources and how you can help

www.apparelysed.com for discussion forums with other spinal cord injured people
www.aspire.org.uk for a range of services and campaigns
www.backuptrust.org.uk for a range of services and campaigns
www.spinal.co.uk for a range of services and campaigns
www.youtube.com for demonstrations of transfers etc

Books on SCI/coping with stress/disability rights etc: available in the psychologist's office

Ask about becoming a volunteer, to provide for example peer support, helping update patient education materials, testing new technology, representing patients on committees and working groups.

A dictionary definition of independence includes these ideas:

not dependent on or controlled by another person or thing, self governing, not influenced by others in ones ideas or conduct.

There are many ways these ideas can be interpreted.

Some people feel unsure if they will be able to achieve independence after injury. They may also attempt to interpret the term independence in exactly the same way they did in the past. A new way of approaching this is required now, a fresh approach that includes the possibility of independence based on your new situation.

Different people are likely to place more emphasis on one aspect of achieving independence in their lives more than another. Much of this emphasis or interpretation can be to do with the personality, background or life experience of the individual such as the stage the person is at in their life.

Changing perception or looking at things differently now after injury can act to empower you in the way you approach your life. Some people have felt a degree of relief from internal mental pressures by thinking differently about independence; beginning to find a way back to having control in their lives on their terms.

Being in control of how things are done for you, or to you, can make a difference to a person's mental attitude to other aspects of their life. Some people are really clear about this. There are some aspects of their support needs that they are willing to negotiate about with regard to the level of control they have and there are other areas where they are absolutely not! Being in charge of how things are done when it involves your body is a really important thing to many people. Control in this area can have a positive effect on self esteem and attitude. However this is an area that requires leadership and training of support workers to develop the standard you want. Where this is not happening it can have a severe impact on an individual's personal morale.

Some examples from real experience:

Independence for me is being able to physically do things for myself, or when not always possible, then clearly directing someone how exactly I want things to be done so I am still exerting control. Being independent gives me selfrespect and I think also challenges people's perceptions of chair users.

Peer Volunteer comment

Take some time to reflect on what is important to you right now.



You may want to set yourself just one or two goals which will give you more control and more independence, in the way that matters to **you**, and this may be very different from the sort of independence others want for you, or for themselves.

This is **your** life and your opinion matters.

Recap Questions

What is meant by a Coping Toolkit

What sort of research can be done to understand coping with SCI?

Is there only one kind of independence after SCI?

What is most important for you to take control of right now?



Returning to work after Spinal Cord Injury

Supporting patients to remain in, or return to, work is seen as part of every healthcare professional's clinical function. Work has been shown to be good for health and wellbeing and much physical impairment is compatible with work given the right type of support. Inpatients at the London Spinal Cord Injury Centre will have the opportunity to discuss return to work during their stay, this includes the option to attend a designated Vocational opportunities clinic..

Statement of fitness for work or "fit note"

If you are sick or off work for more than seven days your employer will probably ask for proof of your illness. Please ask your medical team for further advice. A fit note is the informal name for the statement of fitness for work. This will help your employer to understand how they might help you to return to work sooner or support you to stay in work.

Your doctor can choose one of two options:

- "You are not fit for work"
- "You may be fit for work"

The fit note also includes:

- More space for your doctor to give general advice about how your illness or injury affects you
- Tick boxes for your doctor to suggest, where appropriate, ways your employer could support your return to work

What does "may be fit for work" mean? Your doctor will choose the "may be fit for work" options if they think that returning to work, with support from your employer, is realistic. Your doctor can give general advice on the fit note about how your illness or injury may affect your ability to work. Discuss this advice with your employer to see if you can return to work for example your doctor may suggest possible changes, such as:

- Returning to work gradually eg. by starting part-time
- Working different hours temporarily
- Performing different duties or tasks
- Having other support to do your job and this may be as advised by specialist occupational therapist

Access to Work

An Access to Work grant is money for practical support to help you do your job. It is for people with a disability, health or mental health condition. The money you receive can help pay for:

- Specialist equipment
- Support Worker
- Travel when you cannot use public transport
- A communicator at a job interview

Any money you get does not have to be paid back and will not affect your other benefits. See below for more information:

www.gov.uk/access-to-work/overview

Disability and Employment Advisors

A Disability and Employment Advisor (DEA) at your local Job Centre can help you find a job or gain new skills and tell you about disability friendly employers in your area. They can also carry out an employment assessment asking you about:

- Skills and experience
- What kind of roles you are interested in

Your DEA can tell you about programs and grants to help you get back into work. These include:

- Work choice to help you find a job, and get support when you start work
- Residential training to give you work experience and training
- Access to work Money towards a support worker or the cost of equipment or travelling to work

Spinal Injuries Association (SIA)

The SIA aims to provide spinal cord injured people with the information, support and encouragement needed when considering returning to work, education or volunteering after injury. Further information is available at **www.spinal.co.uk/page/Workwise**. The SIA offer practical help with several services:

- Advice Line which is accessible at www.spinal.co.uk/page/advice-line or 0845 678 6633
- **SIA Academy Master Class options:** life and work after spinal cord injury. More information on the website
- **Employment clinics** SIA regularly participate in vocational opportunities clinics at the London Spinal Cord Injury Centre and other spinal cord injury centres
- Work Matters is one of the information booklets enclosed within the SIA Moving Forward publication contained within the DVD at the back of the LSCIC Education Pack.

London Spinal Cord Injury Centre



Patient Education Research
The areas of research into spinal cord repair		
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Many years of spinal cord injury research has produced a wealth of discoveries that are making the repair of injured spinal cords an achievable goal. However, considering the complexity of spinal cord injury, discovering successful ways to repair injuries is not an easy task.

As investigators try to understand the mechanisms that either inhibit or promote new growth in the spinal cord,

they are making surprising discoveries, not just about how neurons and their axons grow in the CNS, but also about why they fail to regenerate after injury in the adult CNS. Understanding the cellular and molecular mechanisms involved in both the working and the damaged spinal cord could point the way to therapies that might prevent secondary damage, encourage axons to grow past injured areas, and reconnect vital neural circuits within the spinal cord and CNS.

There has been successful research in a number of fields that may someday help people with spinal cord injuries. Genetic studies have revealed a number of molecules that encourage axon growth in the developing CNS but prevent it in the adult. Research into embryonic and adult stem cell biology has furthered knowledge about how cells communicate with each other. Basic research has helped describe the mechanisms involved in the mysterious process of programmed cell death, in which large groups of seemingly healthy cells self-destruct. New rehabilitation therapies that retrain neural circuits through forced motion and electrical stimulation of muscle groups are helping injured patients regain lost function.

A spinal cord injury is complex. Repairing it has to take into account all of the different kinds of damage that occur during and after the injury. Because the molecular and cellular environment of the spinal cord is constantly changing from the moment of injury until several weeks or even months later, combination therapies will have to be designed to address specific types of damage at different points in time.

Using what they know about the mechanisms that cause secondary damage, researchers are creating and testing neuroprotective therapies to prevent the spread of post-injury damage and preserve surrounding tissue.

Some of the findings in these different areas follow:

Stopping excitotoxicity

When nerve cells die, they release excessive amounts of a neurotransmitter which pushes cells into overdrive and self-destruction. Researchers are investigating compounds that could keep nerve cells from responding to these neurotranmitters potentially minimising the extent of secondary damage.

Controlling inflammation

Sometime within the first 12 hours after injury, the first wave of immune cells enters the damaged spinal cord to protect it from infection and clean up dead nerve cells. The actions of these immune cells and the messenger molecules they release, called cytokines, are the hallmarks of inflammation in the spinal cord.

Currently researchers are looking for ways to control these immune system cells and the molecules they produce by encouraging their potential for neuroprotection and minimising their neurotoxic effects. One approach being tested clinically is to exploit the ability of a type of immune cell, a macrophage, to mount a healing response by injecting them into injured spinal cords. Because of the possibility that these cells can also damage tissue, they must be very carefully controlled if they are to be used therapeutically.

Clinical investigators are also looking at how cooling the body protects surviving spinal cord tissue and nerve cells.

Promoting regeneration

Researchers are experimenting with cell grafts transplanted into the injured spinal cord that act as bridges across injured areas to reconnect cut axons, or that supply nerve cells to act as relays. Several types of cells have been studied for their potential to promote regeneration and repair, including Schwann cells, olfactory ensheathing glia, fetal spinal cord cells, embryonic stem cells and adult stem cells Stem cells are capable of dividing and yielding almost all the cell types of the body, including those of the spinal cord. Their potential to treat spinal cord injury is being investigated eagerly, but there are many things about stem cells that researchers still need to understand. For example, researchers know there are many different kinds of chemical signals that tell a stem cell what to do. Some of these are internal to the stem cell, but many others are external - within the cellular environment - and will have to be recreated in the transplant region to encourage proper growth. Because of the complexities involved in stem cell treatment, researchers expect these kinds of therapies to be possible only after much more research is done.

Stimulating regrowth of axons

Stimulating the regeneration of axons is a key component of spinal cord repair because every axon in the injured spinal cord that can be reconnected increases the chances for recovery of function.

Research on many fronts reveals that getting axons to grow after injury is a complicated task. CNS neurons have the capacity to regenerate, but the environment in the adult spinal cord does not encourage growth. Not only does it lack the growth-promoting molecules that are present in the developing CNS, it also contains substances that actively inhibit axon growth. For axon regeneration to be successful, the environment has to be changed to turn off the inhibitors and turn on the promoters.

Investigators are looking for ways to take advantage of the chemicals that drive or halt axon growth: growth-promoting and growth-inhibiting substances, neurotrophic factors, and guidance molecules.

Researchers hope that combining these strategies to encourage growth, clear away debris and target axon connections could reconnect the spinal cord. Of course, all these therapies would have to be provided in the right amounts, in the right places, and at the right times. As researchers learn more and understand more about the intricacies of axon growth and regeneration, combining therapies could become a powerful treatment for spinal cord injury.

Clinical Research



Advances in basic research are also being matched by progress in clinical research, especially in understanding the kinds of physical rehabilitation that work best to restore function. Some of the more promising rehabilitation techniques are helping spinal cord injury patients become more mobile eg with functional electrical stimulation, robots and other technology to help replace lost function resulting from the SCI. They also help exercise paralysed muscles, which can provide significant cardiovascular benefits. For some systems, few people use them because the movements are so robotic, they require surgery and electrode placement, and the computer interface systems are still limited. Bioengineers are working to develop more natural interfaces.

As well as research on the spinal cord itself there are many researchers working on helping to minimise the specific problems people with SCI report eg Improving bladder& bowel control, understanding changes in sexual and reproductive function treating pain, controlling spasticity, improving arm function and reducing bone loss. Other groups are looking at how people with SCI adapt to their SCI and how rehabilitation programmes can best help. Although clinical trials are by nature unproven therapies, there are some key differences that need to be understood before enrolling in either. The characteristics of each are summarised below:

An Unproven Therapy usually:

- Charges a fee for the therapy
- Provides only anecdotal information (such as personal testimonials) as evidence of success
- Does not provide efficacy and other data to the scientific community
- Is heavily marketed via the internet and glossy brochures
- Has not been approved by a relevant government body (such as FDA in the US or EMEA in Europe)
- Has not been listed as a clinical trial on a reputable clinical trial website (such as www.clinicaltrials.gov).

A Clinical Trial however:

- Is always listed on reputable clinical trial websites (such as http://clinicaltrials.gov)
- Does not charge a fee for the therapy
- Has followed a strict regulatory process in terms of the feasibility of the science and the mitigation of risk
- Provides structured studies with large bodies of clinical data for statistically valid evaluation of a therapy to determine safety and reports efficacy and other data back to scientific community via peer review.

Where can I get more information?

The following links are for reputable glossaries about Spinal Cord Injury:

SCI-INFO-PAGES www.sci-info-pages.com/glossary.html

Spinal Research www.spinal-research.org/display_page.asp?section=main&search=1&id=90

ISSCR ww.isscr.org/public/glossary.htm

Wings For Life www.wingsforlife.com/glossary.php

Cure Paralysis Now www.scicure.org/glossary.htm



Many clinics that are offering stem cell treatments make claims about what stem cells can and cannot do that are not supported by our understanding of science. The information at **www.closerlookatstemcells.org** corrects some of the misinformation that is being widely circulated.



The London Spinal Cord Injury Centre is leading in, and participating in several research projects. Speak with your Consultant or a member of the research team to find out more.



Recap Questions

The areas of research into spinal cord repair

The difference between a clinical trial and an unproven treatment

Where to get reliable information on SCI research

Where to find out the research London Spinal Cord Injury Centre is involved in

Notes



Sex and sexual function

Anatomy of the male sex organs

Scrotum

- Pouch of skin that contains the testes and its tubes
- Assists in keeping the testes at the right temperature for sperm production (2 degrees below body temperature).

Testes

- Egg shape glands that produce the sperm
- Also produce the male sex hormone testosterone.

Penis

- Contains the urethra
- It consists of 3 cylindrical tubes made of erectile tissue
- These tubes fill with blood during sexual stimulation (producing an erection)
- The erection assist in depositing the sperm effectively
- The end of the penis is slightly larger and is called the glans.

Epididymus

• The long tube, behind the testes in the scrotum in which the sperm are stored.

Seminal vesicles

• Small glands located behind the bladder that add fluid to the sperm.

Prostate gland

- Small gland at the bottom of the bladder which adds more fluid to the sperm
- The urethra passes through it.

Ejaculatory duct

- Small tube that carries the semen (sperm plus added fluids) into the urethra
- This occurs close to the time of ejaculation.

Urethra

- The thin elastic tube that runs through the penis.
- During ejaculation, the bladder is closed off so that urine does not escape.
- The urethra carries the semen to the outside of the body.

Sexual function is a complex interaction between:

- Spinal cord reflexes
- Influences from the brain
- Hormones
- Psychological factors

Nerve Supply:

The important parts of the spinal cord for sexual function in males are:

- Sensation (to perineum) S2-4.
- Erection T11,12 and S2-4.
- Ejaculation T11,12 and S2-4.

Male Sexual Response Cycle

What happens when a man becomes aroused?

Sexual arousal is a result of a combination of signals that stimulate our senses including:

- Smells
- Sounds
- Seeing something sexually exciting
- Touch especially in erogenous zones.

The physical signs of arousal that the body shows include:

- Penis becomes erect
- Scrotum tenses and testes rise
- Emission and ejaculation may occur
- Nipples become erect
- Muscles tense
- Breathing becomes rapid
- Pulse and blood pressure rises
- Skin becomes flushed.

Orgasm is the culmination of all these feelings: when orgasm occurs there is a pumping action that discharges semen from the penis in spurts.

Following orgasm:

- Muscle tension decreases pulse, blood pressure and breathing gradually return to normal
- Relaxation occurs.

Erogenous Zones

Remember, the erogenous zones are not only the genitals but also the neck, ears, lips and almost any other part of the body. Some or all of these areas may contribute to arousal and stimulation.

Reflexogenic Vs. Psychogenic Stimulation

In the male:

Erections can be either:

Psychogenic

Caused by a message sent from the brain e.g. seeing an attractive person, watching an erotic movie, or fantasizing.

Reflexogenic

Caused by direct stimulation.

Combination of Both

Sexual function following spinal cord injury depends primarily on:

- Level of injury
- Completeness of injury
- Time since the injury may also be important.

The main aspects of sexual function that, may have been affected in males are:

- Sensation in genital and other areas below the level of injury.
- Orgasm may be changed.
- Ability to achieve and sustain an erection may be affected.
- Ability to ejaculate may be affected.

Treatment of Sensory/Orgasmic Problems

- Sensation may improve with time
- Explore erogenous zones/areas above the level of injury ...these may become extra-sensitive
- Orgasm may not be the same as before but can be just as good
- Don't expect miracles the first time!

Intercourse Positions

- Muscle weakness, spasm or balance problems may make sexual activity more difficult than before
- Experiment with other positions
- A member of the team or your local health professional can give you advice about other positions to try or how to manage spasms or lack of balance
- Communication with partner is very important.

Bladder and Bowel Problems

A member of the team can also give you advice about:

- Avoiding bladder or bowel accidents
- Problems related to your type of bladder management and
- How to overcome them.

Spasticity

• Spasms may aid or interfere with sexual activity.

Autonomic Dysreflexia (AD)

- If you are prone to AD this can sometimes occur during sexual activity, especially with ejaculation/orgasm
- If severe, the activity should be temporarily ceased
- Check other causes of AD i.e. bladder/bowel.

Contraception

• Even if you do not think you ejaculate as before, you may still be able to get your partner pregnant.

Treatment of Problems with Erections

Different Positions

- Some people find that using particular positions during intercourse help maintain erections better
- This requires patience, experimentation and communication with partner.

Vacuum Devices

- Small vacuum pump is applied to penis to draw blood in
- Elastic ring is applied to base to stop the erection subsiding - tends to cause slightly "bent" erection
- Must not be left in place for more than 30 minutes
 - Advantage-Non-invasiveDisadvantage-Erection does not look normal.

Penile Injections (Caverjet)

- Injection of medication directly into side of penis.
- The medication (Alprostadil/Prostaglandin E2) assists the blood to enter the penis and produce an erection.
 - Advantage Erection is more normal looking
 - **Disadvantage** Care must be taken with dose given or erection can last too long and this is dangerous
 - Overcoming the whole idea of "injections".

Intra-urethral Pellets (MUSE)

- Small pellet the size of grain of rice put into urethra
- Same drug as the injections (Alprostadil)

Advantage-No injectionsDisadvantage-Sometimes does not work as well as injections.

Penile Implants

- Complex surgical procedure to implant a device into penis to assist with erection
- Rarely used because of complications but is sometimes appropriate.

Oral Medications (e.g. Viagra, Levitra + Cialis)

- Tablet form
- Only works if there is arousal stimulation

Advantage - No injections

Disadvantage - May have side effects and need to be taken in advance of activity

Vulva

• Folds of skin at the entrance to the vagina.

Outer Labia

- Larger folds on the outside
- These have skin and hair. Contain glands that produce the lubrication fluid needed for intercourse.

Inner Labia

- Smaller folds of skin inside the larger folds
- These are soft, pink and moistened by secretions.

Clitoris

- The external projection of this organ is located just above the urethral opening at the top of the inner labia
- Highly sensitive and its only real purpose is for pleasure
- Made of the same type of erectile tissue as found in the penis.

Vagina

- Hollow muscular tube / opening into the body
- Has a moist lining which is made up of folds of skin
- It lengthens and widens with sexual intercourse
- It accepts the penis during sex
- Also the passageway during childbirth.

Fallopian Tubes

- These tubes are attached to the top of the uterus
- Each month they carry an egg from the ovaries to the uterus, ready to be fertilized

Uterus

- Pear shaped muscular organ located in the pelvis
- Its purpose is to carry and nurture a child
- Each month of the female cycle it builds up its lining, if no fertilised egg is received it expels the lining in a process called menstruation (a period)
- The cervix is the opening of the uterus into the vagina.

Ovaries

- Two small organs located in the pelvis they produce and store the eggs until they are ready to be released each month
- They also produce the female sex hormones oestrogen and Progesterone.

Sexual function is a complex interaction between:

- Spinal cord reflexes
- Influences from the brain
- Hormones
- Psychological factors

Nerve Supply

The important parts of the spinal cord for sexual function in Females are:

- Sensation (to perineum) S2-4.
- Clitoral erection T11,12 and S2-4.
- Vaginal Lubrication T11,12 and S2-4.
- Female Sexual Response Cycle

What happens when a woman gets aroused?

- Vagina moistens.
- Clitoris swells.
- Labia swell and open.
- Uterus contracts.
- Nipples become erect.
- Muscles tense.
- Breasts enlarge.
- Breathing becomes more rapid.
- Pulse and blood pressure rise.
- Skin becomes flushed.

Orgasm is the culmination of all these feelings, it involves: withdrawal of the clitoris from its normal position. strong contraction of the muscles of the vaginal walls and rectal area. tensing of other muscles.

Following orgasm there is:

- Muscle relaxation
- Gradual fall in pulse, blood pressure and breathing.

Erogenous Zones

Remember, the erogenous zones are not only the genitals but also the neck, ears, lips and almost any other part of the body. Some or all of these areas may contribute to arousal and stimulation.

Sexual function following spinal cord injury depends primarily on:

- Level of injury
- Completeness of injury
- Time since the injury may also be important.

The main aspects of sexual function that may have been affected in females are:

- Sensation in genital and other areas below the level of injury
- Orgasm may be changed
- The ability to achieve Vaginal lubrication may be affected
- The degree of paralysis of muscles around hips, pelvis and legs may be important for both sexes with respect to positioning for sexual activity and intercourse.

Treatment of Sensory/Orgasmic Problems

- Sensation may improve with time
- Explore erogenous zones/areas above the level of injury ...these may become extra-sensitive
- Orgasm may not be the same as before but can be just as good
- Don't expect miracles the first time!!

Intercourse Positions

- Muscle weakness, spasm or balance problems may make sexual activity more difficult than before
- Experiment with other positions
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- Communication with partner is very important.

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A member of the team can also give you advice about:

- Avoiding bladder or bowel accidents
- Problems related to your type of bladder management and how to overcome them.

Spasticity

• Spasms may aid or interfere with sexual activity.

Autonomic Dysreflexia (AD)

- If you are prone to AD this can sometimes occur during sexual activity, especially with ejaculation/orgasm
- If severe, the activity should be temporarily ceased
- Check other causes of AD i.e. bladder/bowel.

Contraception

- Menstruation (period) usually begins a few months after spinal cord injury
- Once menstruation begins again, you can get pregnant
- Fertility in women with SCI is usually normal unless there is some other fertility problem
- Contraception will be needed unless you are attempting to get pregnant.

Overcoming Difficulties

General Points

While sexual activity following SCI may be different from before this does not mean that it cannot be exciting, stimulating and satisfying. You can have a sexually active life and maintain intimate relationships after spinal cord injury.

Remember:

- Sex is a natural part of life and we are all sexual beings this has not changed simply because of your SCI.
- Sex and sexuality are important parts of your overall rehabilitation
 - the staff in the Spinal Centre are happy to discuss issues with you whenever you feel ready
- There is more to sex than just sexual intercourse e.g. foreplay, touching, caressing, exploring, oral sex, masturbation/mutual masturbation.
- The inability to move much does not mean the inability to please or be pleased.
- Loss of genital function and/or sensation does not mean loss of your sexuality.

Menstruation returns to a normal pattern after the acute physical and psychological trauma has passed. This may take anywhere from 6 weeks to 2 years after your spinal cord injury but usually within 1 year.

The uterus (womb) works normally through conception and pregnancy, and fertility for women with a spinal cord injury is usually unaffected in the longer term.

Pregnancy in SCI Women

Many spinal cord injured women, both those with tetraplegia and paraplegia, have had successful pregnancies and healthy children.

If you are planning to get pregnant you should discuss this with your family doctor, obstetrician and SCI doctor.

Some medications that you are taking may need to be stopped prior to conceiving. As a general rule of thumb, drugs are normally avoided during pregnancy and especially during the first 12 weeks.

- The uterus (womb) works normally during conception, pregnancy and childbirth
- There may be a slightly higher incidence of complications during pregnancy and labour
- Many SCI women have relatively few problems and have non-complicated pregnancies and deliveries.

Issues for SCI Women during Pregnancy

Respiratory Some women with tetraplegia have some respiratory problems due to the womb pressing up underneath the diaphragm in the later stages of the pregnancy.

Bladder Management The normal bladder routine is likely to be upset during pregnancy. If you are self-catheterising or bladder trained, these may become difficult in the last 3 months of pregnancy. This is an individual thing and best discussed with the obstetrician if and when problems arise.

Urinary tract infection is one of the most common causes of premature labour.

Fertility and Pregnancy - Women

Bowel Management Constipation is a common problem in pregnancy.

Increase the amount of fibre in your diet, laxatives may need to be started or increased in number.

Posture Posture and balance in the wheelchair may become a problem as the pregnancy progresses due to the weight of the baby pulling the body forward. For women with lower level injuries the natural tendency is to arch the back to counterbalance the weight, this may lead to back pain.

Your physiotherapist can give you advice on:

- Appropriate exercises for the lower trunk during pregnancy and after the baby is born
- Back care and the increased risk of damage to the back during pregnancy.

Transfers Wheelchair transfers may become increasingly difficult because of increasing weight and decreasing balance. In some cases women may have to resort to other means of transferring, for example, using a hoist.

Pressure Relief Pressure sores are one of the most common problems associated with pregnancy and one, which is readily avoided.

- Continue to do regular skin checks to detect any problems early
- Pressure relief requirements are usually unchanged during the first half of the pregnancy
- During the second half of the pregnancy, due to increasing weight and decreasing balance, pressure may become a problem
- If using a foam cushion you may need to change to a better pressure relieving cushion
- A pressure relieving mattress may also be required for both skin care and comfort.

Sleeping Position In the early stages of pregnancy, prone lying is still possible. As pregnancy progresses, lying flat on the back or stomach will become too difficult, especially for those with tetraplegia because breathing becomes difficult due to pressure on the diaphragm by the enlarged uterus.

- Pressure on the large vessels in the abdomen will decrease circulatory return
- Nausea and dizziness are warning signs that you should not sleep or exercise while lying on your back
- The use of a partial sitting position when in bed is often more comfortable, as it can help relieve heartburn (a common discomfort amongst all pregnant women, able-bodied or not).

Note This, however, may increase pressure and shearing on the skin of the buttocks. Lying on your side in partial sitting/lying should be the position of choice and comfort.

Labour It is sometimes difficult to tell when labour starts. Some obstetricians prefer admittance to hospital in the last few weeks of pregnancy to the onset of labour. This is a very individual thing and best discussed with the doctor.

The choice between a vaginal delivery and an elective caesarean section is influenced by many factors including the mother's general health and position of the baby in the womb. The potential for autonomic dysreflexia during labour for women with injuries above T6 exists, but in practice this a rare problem.

Please discuss with your SCIC doctor who can liaise with your local team regarding the effects the SCI will have during pregnancy and labour.

The SIA run a masterclass for parenting after SCI which you may find useful.

Fertility - Men

Fertility in men with a spinal cord injury may be markedly reduced.

This depends to some extent on:

- The level of the injury.
- Whether the injury is complete or incomplete.

Reduction in fertility occurs for 2 main reasons:

- Ejaculation is difficult.
- Semen / sperm quality is reduced (especially the motility (speed and quality of movement) of the sperm)

There are many possible reasons for reduction in semen quality including:

- Recurrent UTIs, prostate or testicular infections
- Increased scrotal temperature
- Infrequent ejaculation leading to stasis
- Method of bladder management

Methods of Semen Retrieval

There are 3 main methods of obtaining semen if ejaculation by natural methods is difficult or impossible. Speak to your doctor or specialist nurse regarding the advantages and disadvantages of each.

Vibroejaculation

- A vibrator is applied to the penis and may stimulate ejaculation
- This usually only works in lesions above T9-10
- It can be done at home
- May cause autonomic dysreflexia in people prone to this (lesions above T6)

Surgical retrieval

This involves a minor operation to retrieve sperm directly. Speak to your doctor or specialist nurse about this.

Electroejaculation

- Vibrators do not work in all cases.
- Electroejaculation involves use of an electrical probe placed into the rectum
- A small electrical current stimulates the nerves of the seminal vesicles (where the semen is stored)
- Causes emission rather than true ejaculation
- This can only be used if you have no sensation in the rectum it cannot be performed at home, only in the spinal cord injury centre
- May also cause autonomic dysreflexia.

The semen that is obtained by both of these methods can then be used for artificial insemination of your partner.

Methods of Improving Semen Quality

Reducing Infections

Be aware of correct methods of bladder management and catheter care etc Infections need to be treated quickly and properly

Reducing High Testicular Temperature

- Wear loose trousers and underpants
- The type of cushion you use may be important
- Sit with legs apart if possible

Improving Low Semen Turnover

• Regular ejaculation by whichever method

Type of Bladder Management

- Self-catheterisation probably best
- IDC or SPC better than reflex voiding (conveen drainage)
- Avoid high bladder pressures whichever method is being used.

A spinal cord injury causes a number of changes in family life and home situations. As you are planning the changes that are necessary in your life to accommodate your needs, remember to include your child in this process.

If you are in hospital, it is important that your child understands why you are away from home and should be able to visit you regularly. If they are not able to visit because of distance, they may be able to speak to you on the telephone. This reassurance is important. Children of different ages understand things at different levels. Explain the effect of your spinal cord injury in a way they can understand.

Parents who are newly injured sometimes express concern about their ability to continue to be parents to their children. You may find yourself wondering about how your child will react to you now you are in a wheelchair. If you have been experiencing feelings of depression or discouragement as part of your adjustment process, you may find yourself questioning your ability to go on caring for your child.

Most children are very accepting and adaptable. They will take their cues on how to respond from those around them. This is why it is very important for you to keep talking openly to your child. Visits home will help you maintain your relationship with your child. Both you, and your children will need time to adjust to the physical changes and understand that this does not change the strength of your relationship.

Helpful suggestions

- Include your child in your rehabilitation program, through hospital visits and weekend leave
- Help your children to meet other families in a similar situation. Give your children time to talk and play with other children
- If your children are old enough, allow them to attend your case conferences, goal plannings and education sessions
- Keep talking with your children about your situation even after returning home.
- Be patient adjustment for children takes time too
- The more successfully you make your adjustment the better it will be for your child, as children use their parents as role models.

Notes



Learning Needs Assessment



Red

You have read the education pack, or discussed it with a Nurse.

Amber

You have successfully completed the quiz at the end of each section.

Green

You have successfully completed the refresher and troubleshooting quiz.

Practical/Direction

You can actively attend to care or successfully direct others to.

Education Pack Given	Sign and Date
Autonomic Dysreflexia	
Bladder Management	
Bowel Management	
Coping and Independence	
Nutrition	
Research	
Respiration	
Returning to work	
Sexual Function	
Skin	
Spinal Cord	

Торіс	Red	Amber	Green	Practical/ Direction
Autonomic Dysreflexia				
Bladder Management				
Bowel Management				
Coping and Independence				
Nutrition				
Research				
Respiration				
Returning to work				
Sexual Function				
Skin				
Spinal Cord				

Nursing staff to sign and date when each level is achieved.

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The Spinal Cord

- 1. The vertebral bones are divided into how many sections?
- **a.** 2
- □ **b.** 4
- **c.** 6
- □ **d.** 5
- 2. What level is your spinal cord injury?

3. Is your injury complete or incomplete and what does this mean?

Bladder Management

1. The major job of the kidney is to

- **a.** Store urine
- **b.** Destroy old blood cells
- **c.** Carry urine to the bladder
- **d.** Filter waste material from the blood

2. Urodynamics is a diagnostic test used to

- **a.** Evaluate kidney function
- **b.** Visualise the kidney and ureters
- **c.** Evaluate bladder and sphincter function
- **d.** Visualise the bladder and urethra

3. The signs and symptoms of a urinary tract infection (UTI) includes which of the following?

- □ a. Temperature / Sweating
- **b.** Sediment in your urine
- **c.** Offensive smelling urine
- □ **d.** Decreased skin tolerance
- **e.** Firing off (Bladder incontinence between catheters)
- □ **f.** Increased spasm activity
- **g.** Double vision
- **h.** Low blood pressure (hypotension)

4. When you are at home, you suspect by your signs and symptoms you have a UTI, what is the first thing you will do?

- □ **a.** Contact your GP
- **b.** Contact your district nurse
- **c.** Collect a fresh urine sample for analysis
- □ **d.** Contact your local SIU

5. Reflux is the

- **a.** Collection of urine in the kidney, causing swelling of the kidney
- **b.** Automatic contraction of the bladder, resulting in urination
- **c.** Back flow of urine from the bladder into the ureters

6. Why is bladder management important?

- **a.** To prevent infections and to protect the kidneys
- **b.** To maintain a fluid restriction
- **c.** To prevent bladder accidents

7. You suspect you have a UTI and you have taken a urine sample to your GP, when should you have antibiotics prescribed?

- **a.** Need not to be used if you are on "clean techniques" for intermittent catheterisation
- **b.** Need to be used only if you have symptoms i.e. temperature, feeling unwell and sensitivity of urine
- **c.** Should be used on a regular basis
- **d.** Should be used only when your urine is cloudy or dark

8. You have and indwelling or supra pubic catheter and it blocks when you are at home, what should you do?

- **a.** Drink more
- **b.** Change catheter
- **c.** Remove catheter and leave it out

9. You are on an intermittent catheter programme. If for any reason you decide to increase your fluid intake, do you

- **a.** Tell your GP
- **b.** Tell your community liaison nurse
- **c.** Increase the number of catheters you do
- **d.** Keep a record of your fluid intake

10. Drinking alcohol affects your bladder management. Which of the following is not true?

- **a.** It decreases your urine output
- **b.** It has a diuretic effect (produces more urine)
- **c.** It diminishes or potentiates the effects of drugs
- **d.** It can alter the reflex activity of bladder muscles
Bowel Management

1. The most important element in establishing a bowel programme without accidents is to

- **a.** Perform your bowel programme every day
- **b.** Maintain a regular and consistent time with your bowel programme
- **c.** Perform your bowel programme at random times throughout the day
- **d.** Use suppositories, laxatives and stool softeners

2. The gastro-colic reflex is a mass movement of bowel content which occurs

- **a.** When you perform your bowel programme
- **b.** Once a day, when you wake up in the morning
- **c.** As soon as food is swallowed
- **d.** Approximately 30 minutes after having a warm drink

3. Faecal / Stool softeners work by

- **a.** Preventing absorption of water from the faeces
- **b.** Setting of reflexes that start movement of the lower bowel
- **c.** Stimulating movements of the stool through the bowel
- **d.** Increasing the bulk of material in the intestines

4. Impaction means that the bowel

- a. Is distended
- **b.** Has too much fluid in it
- **c.** Has become "sluggish"
- **d.** s blocked by a large mass of stool

5. List 3 elements that are important for a good bowel routine!

6. After spinal cord injury, the external anal sphincter functions differently because

- **a.** Control from the brain is gone
- **b.** Peristalsis is slowed down
- **c.** Digestion is slowed down
- **d.** The rectum is paralysed
- 7. You suspect you might be getting constipated and you are currently performing your bowel programme on alternate days. As well as drinking more fluids and eating more fibre, you should
- **a.** Call the doctor
- **b.** Perform an enema
- **c.** Eat some yoghurt
- □ **d.** Repeat the bowel programme

8. After going out for a meal the previous evening, you wake up finding you have diarrhoea, which of the following should you not do?

- **a.** Drink more.
- **b.** Observe your skin and turn more often.
- **c.** Sit on an inco pad until the diarrhoea subsides.
- **d.** Stop Lactulose and Dioctyl until diarrhoea subsides.

9. A high fibre diet prevents constipation, which of the following is not high fibre?

- **a.** Whole grain, bread and cereals.
- **b.** Dried fruits, prunes, figs and raisins.
- **c.** Whole milk, ice cream and cheese.
- **d.** Fresh fruit and vegetables.

Skin/Pressure Area Care

1. Being sure that skin checks are done and making decisions regarding skin care is the responsibility of

- □ **a.** A care attendant
- **b.** The spinal cord injured person
- **c.** A family member
- **d.** The doctor

2. Doing pressure relief when sitting in your wheelchair relieves pressure from your

- **a.** Mid back
- **b.** Hips
- **c.** Ischia/sitting bones
- □ **d.** Sacrum

3. The most important thing to do if you discover a red or dark spot caused by pressure is to

- **a.** Call the doctor
- **b.** Go to bed
- **c.** Put antiseptic on the area
- □ **d.** Stay off the area

4. Pressure sores result from pressure on the

- □ **a.** Blood vessels
- **b.** Nerves
- **c.** Muscles
- **d.** Glands

5. List 5 extremely vulnerable areas of skin breakdown!

6. When you change position to do a pressure relief, it is a good idea to hold your position for a minimum of

- **a.** 4 minutes every hour
- **b.** 30 seconds every hour
- **c.** 1 minute every hour
- **d.** 2 minutes every hour

7. Shearing force damages the skin by causing

- **a.** Removal of top layers of skin and stretching of blood vessels
- **b.** Increased spasticity and muscle tone
- **c.** Stiffening of the joint and tearing the muscle
- **d.** Prolonged block of blood flow to an area of the skin

8. You have just spilt boiling water on your arm. A quick look shows several blisters forming, what is the first thing you should do?

- **a.** Apply burn ointment or butter
- **b.** Call the doctor
- **c.** Wrap the area with a clean cloth
- \Box d. Soak the area in cold water for 5 10 minutes, then seek medical advice

9. When wearing new clothes, should you

- □ **a.** Wear a bigger size
- **b.** Never wear anything other than a track suit and trainers
- **c.** Check your skin after half an hour.
- **d.** Check your skin on return to bed.

10. When checking your skin, as well as looking at it in a mirror, what else should you do

- **a.** Have a wash
- **b.** Feel your skin for heat and lumps
- **c.** Put cream on your skin
- **d.** Put powder on your skin

Autonomic Dysreflexia

- 1. Which of the following does not occur as a complication of autonomic dysreflexia?
- **a.** Stroke
- □ **b.** Death
- **c.** Low blood pressure
- □ **d.** High blood pressure
- 2. You are on an intermittent catheter regime. You are sitting in your chair when you experience symptoms of autonomic dysreflexia, what is the first thing you should do?
- **a.** Call the doctor.
- **b.** Do a catheter.
- **c.** Evacuate your bowel.
- **d.** Lay down.
- 3. At what level does a person with a spinal cord injury not have to worry about the effects of autonomic dysreflexia?
- **a.** C3 complete tetraplegia
- □ **b.** T5 complete paraplegia
- **c.** T12 complete paraplegia
- □ **d.** C5 complete tetraplegia

4. Some symptoms of autonomic dysreflexia include

- **a.** Headache, increased blood pressure, nausea, vomiting and blotching of skin
- **b.** Headache, increased blood pressure, sweating and blotching of skin
- **c.** Headache, increased blood pressure, fever, anxiety, runny nose and blotching of skin
- **d.** Headache, decreased blood pressure, joint pain, sweating and blotching of skin

5. List 3 ways in which autonomic dysreflexia can be prevented!

6. You keep having mild autonomic dysreflexia attacks, what should you not do?

- **a.** Consult your doctor
- **b.** Check for signs of infection or constipation
- **c.** Consult your district nurse
- **d.** Ignore the problem and hope it goes away

7. You are in bed asleep and you wake up with a pounding headache, what should you not do?

- □ **a.** Go back to sleep
- 🗆 b. Sit up
- **c.** Do a catheter
- □ **d.** Evacuate your bowel

8. Which of the following is not a cause of autonomic dysreflexia?

- **a.** Manual evacuation or rectal examination
- **b.** Ingrowing toe nails or pressure sores
- **c.** Sexual intercourse
- □ **d.** Menstruation or labour
- **e.** Toothache or earache. arguable
- **f.** Full bladder or bladder investigations

9. Where should you keep your autonomic dysreflexia card?

- **a.** In your purse or wallet that is with you at all times
- **b.** By your bed
- □ **c.** At your GP surgery
- **d.** In a safe place at home

10. What is the name of the drug, which lowers BP in the event of autonomic dysreflexia, and how should it be taken?

London Spinal Cord Injury Centre