You will need to bring this booklet into hospital with you.
Admission to hospital can be a daunting experience for most people, the following information is designed to give you information about your stay in hospital and what to expect during your stay. This information is intended as a guide only and may vary slightly depending upon your individual requirements.

The Walton Centre is a Regional unit that admits patients 24 hours a day depending upon the urgency of their condition. It is because of this that you need to ring the hospital the morning of your admission to check that there is a bed available for you. Ring 0151 525 3611 and ask the switchboard to bleep the bed manager on bleep 2009. We appreciate that you need to make arrangements for your hospital admission and discharge and we will make every effort to accommodate you, however, occasionally it is not possible and we do not want you to travel a long journey to be disappointed.

The procedure you are being admitted for is **UNTETHERING OF SPINAL CORD**

This booklet contains information about your hospital admission, procedure and care. It also has a glossary of terms (page 14 +15) you may find mentioned in this booklet or hear your surgeon use. From page 16 onward is physiotherapy information, giving you some guidance and describing the exercises you will need to do.

Should you have any questions after reading this please do not hesitate to contact the Spinal Nurse Specialist on 0151 529 8853.
What does the spine compose of?

The spinal column is a tower of bones (vertebra) that all sit on top of each other to form your vertebral column (back bone), from the base of your skull (cervical vertebra) to your tail bone (coccyx) just above your buttocks. These bones form a protective tube in which your spinal cord can run, with the bony column circling all around the spinal cord to protect it.

Your spinal cord runs down the middle of this cylindrical tower of bones, and at the level of each bone (vertebra) it sends out 2 nerves, one on the left side and one on the right side.

These nerves contain millions of nerve fibres and work almost like a telephone exchange. They carry messages from all parts of the body, inside and outside, back to our spinal cord and from there up the spinal cord to the brain. They also take messages from the brain to the body, for example, to tell our muscles to move our legs, or tell the bladder to open the valves that allow us to pass urine. These nerves contain a mixture of movement (motor) nerves and sensation (sensory) nerves.

They also have their own areas of responsibility. The nerves in the neck part of the spine (cervical) are mostly responsible for the arms, hands, fingers and the area of the body from the neck to approx just above nipple line. The nerves in the Trunk (Thoracic) part of the spine, are mostly responsible for the chest and trunk area of the body.
The nerves in the lower back (lumbar and sacral) carry the messages for everything below the waist, including legs, feet and also bladder bowel and sexual function.

**Tethered Cord Syndrome**

Tethered cord syndrome is a complex condition that starts before we are born, as we are constructed, and grow in the womb. Soon after conception, as a baby develops in the womb, cells form together to build the spinal column. If this develops in a disorganised way the spinal column does not form fully and the spinal cord and/or filum terminale can get trapped amidst this area of quickly developing structures. The spinal cord is then said to be tethered, which means it is abnormally attached within the bony spine. 80% of these abnormal developments are in the lower section of the spine (lumbar and sacral).

Normally the spinal cord can move freely as you bend, stretch and grow. When these abnormal tissue attachments are present it limits the movement of the spinal cord within the bony spinal column. This is closely linked to a condition known as spina bifida occulta, which is a term used to describe an abnormality of the bone structure of the spine. This only causes a problem when there is an additional abnormality like a Tethered Cord. On page 14 and 15 you will find a list of terms and conditions some of which you may have heard your Doctor use. There may not be any or there may be a few that are relevant to you and your condition.

Spinal cord tethering can also occur following an injury, infection or surgery to the spine when development of scar tissue can attach/tether the cord abnormally.

As we have already mentioned the nerves at the bottom of the spine, carry the messages important for movement and sensation to the legs, feet and toes and they are also very important for bladder bowel and sexual function.
Exercise 6

Start Position—Lying on your back with one leg straight and the other leg bent. (You can vary the exercise by having your foot pointing either upwards, inwards or outwards).

Action—Exercise your straight leg by pulling the toes up, straightening the knee and lifting the leg 20cm off the bed. Hold for approximately 5 seconds, then slowly relax.

Repeat 10 times with both legs

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Tethered cord Syndrome

The abnormal stretching puts tension on the spinal cord and nerves, this causes problems with the messages, getting to and from the legs, feet, toes, bladder, bowel and can cause some problems with sexual function.

Tethered cord syndrome tends to be a progressive disorder, and can remain undiagnosed until adulthood. This is because the spinal cord and nerves are stretched slowly over time, and general physical wear and tear of daily movement adds to the situation.

It is sometimes only recognised after subtle symptoms become more obvious. People can experience some problems passing urine, unusual patches of sensation in the feet or legs. These symptoms are all due to the abnormal stretching of the nerves that have the responsibility for these areas. Because the symptoms often develop very slowly over time, it may have been a while before you have realised there is a problem. Slight changes can often be attributed to other more common conditions or reasons.

Symptoms of a Tethered Cord can include:

1. Persistent back pain.
2. Changes in sensation in the legs or feet.
3. Difficulty in walking.
5. Not being able to empty the bladder fully.
6. Frequent urine infections.
7. An unequal appearance in the size of a person's legs or feet, so one side will appear smaller than the other.

As you can see these symptoms can easily be associated with other more common conditions.
**Treatment**

**Conservative Management**

This is an option if tethered cord has been recognised early and there are minimal symptoms. If your condition remains unchanged then it may be possible to monitor your condition, and act only if there are any changes.

**Treatment**

It is more likely that you are reading this because you are considering an operation.

The operation is performed to release the spinal cord from where it is attached, in order for it to hang freely within the spinal canal, and prevent any further stretching of the nerve roots or spinal cord. This is performed to prevent any further deterioration. It is very unlikely to improve any symptoms that you have already developed.

**Reason for surgery**

The goal of an operation is to prevent any further deterioration in the function of the spinal cord and nerves. As has already been mentioned it is unlikely that surgery will make any improvement to any symptoms that you already have. This is due to some nerves already being damaged from the abnormal stretching that has already happened.

If it is not treated, and you already have developed symptoms, then it is likely that you will continue to get more problems and deterioration as the nerves continue to be stretched and become more damaged, preventing messages from travelling through them.

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**Exercise 4**

**Start Position**—Lying on your back. Bend one leg and put your foot on the bed and put a cushion under the other knee.

**Action**—Exercise your straight leg by pulling your foot and toes up, tightening your thigh muscle and straightening the knee (keep knee on the cushion), Hold for approximately 5 seconds and then slowly relax.

Repeat 10 times

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**Exercise 5**

**Start Position**—Lying on your back with legs straight.

**Action**—Bend your ankles and push your knees down firmly against the bed. Hold for 5 seconds and then relax

Repeat 10 times
**Exercise 1**

**Start Position**—Lying on your back

**Action**—Bend your leg and bring your knee towards your chest and your heel towards your bottom.

Repeat 10 times

**Exercise 2**

**Start Position**—Lying on your back or sitting

**Action**—Bend and Straighten your ankles briskly. If you keep your knees straight during the exercise you will stretch your calf muscles.

Repeat 10 times

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**Risks of Surgery**

With any type of surgery there are risks, and although it is not common for them to happen, it is important that you understand that there is a potential for them to occur.

The risks of surgery will be discussed in detail with you by your doctor, before your surgery.

The risks with untethering of the spinal cord include:-

1. Risk from having a general anaesthetic
2. The risk of a leak of the spinal fluid (CSF), that flows around your brain and spinal cord.
3. Infection either in your wound and/or in the spinal fluid
4. Haematoma (blood clot)
5. Increase in pain
6. Transient weakness, A temporary weakness that occurs due to a malfunction of the nerves, as a consequence of the surgical procedure. This is a common complication that resolves over time.
7. The risk of damage to the nerves, causing your symptoms to become worse, leading to problems with your legs, bladder, bowel and sexual function. In extreme cases this could also mean paralysis, unable to move from the waist down, but this is an exceptionally rare complication.
Pre operative assessment

You will be brought into the hospital for your pre operative assessment. This includes being assessed by the anaesthetist he/she will have a chat with you, discuss any relevant medical history and explain what having an anaesthetic will involve.

You may have some blood tests performed, a member of the nursing and medical team will discuss your medical history with you and you will be examined. If any X-rays or a heart trace (ECG) are required these will also be done. It would be helpful if you could bring with you any medication that you are taking or a list of your medication and doses so the doctor can prescribe them

This may all be done at the pre-operative assessment clinic and an appointment will be organised for you and sent to you if you are required to attend for this.

If you are admitted straight to the ward, without attending the pre-operative clinic, do not worry, all your investigations will be performed the day you are admitted.

In all cases your surgery will normally be the day following your admission, you will not go home overnight.

There may be periods of waiting on your admission day, everything, will be done as quickly as possible but I am sure you will appreciate that the medical staff also have many other patients to care for, so please be patient.

It is advisable not to bring any valuables with you into hospital, as the hospital does not accept any responsibility for their safety.

You will be able to eat and drink up to midnight on the evening before your surgery and in some cases up to 6am on the morning of your surgery. This varies depending on what time you are due to have your operation. The ward staff will be able to clarify this for you.

Physiotherapy following Untethering of Spinal Cord

If you have been advised a period of bed rest following your operation it is important to maintain your circulation and your muscle tone to assist in the recovery process.

The following exercises should be carried out several times a day until you are able to get up out of bed.

Once you are allowed to get up out of bed the physiotherapist will review your mobility if you experience any difficulties.

Breathing Exercises

Take a deep breath in, hold, and breathe out slowly, repeat 3 times. Return to breathing normally for a minute. Repeat the deep breathing for 3 more cycles.

Lower limb Exercises

These exercises should be performed slowly and carefully to ensure no discomfort is felt.

Exercise 1

Start Position—Lying on your back with knees together and bent

Action—Slowly roll your knees towards your chest and your heel towards your bottom.

Repeat 10 times
Diastematomyelia

(Split spinal cord) – The spinal cord is separated into two by a bony abnormality. The bony abnormality sits like an island in the middle with the spinal cord separating to run either side of it and then sometimes the spinal cord comes back together after it goes past it.

Laminectomy

Removal of the lamina, which is part of the bony structure of the spinal bones, usually done to reduce pressure from bone on the spinal cord and nerves or to allow good access for surgery.

Dermal Sinus

A tract lined by skin cells that goes down from the skin to anywhere along the back of the spine or spinal cord.

Spinal Dysraphism

This term encompasses all defects associated with malformations of the back of the spine.

Meningocele

A cystic filled cavity that comes through a bony deformity of the spine and is lined on the inside with the same coverings as the spinal cord, but does not contain any nerves.

Myelomeningocele

This is the same as a Meningocele (see above) except there are elements of the spinal cord and nerves within the cystic filled cavity.

The Day of your Operation

You will be kept fasted (nothing to eat or drink) and need to wear a theatre gown following your morning bath or shower.

Your details will be checked with you on the ward, before you go to theatre. You will be wearing a wrist band with your details on and have to answer a list of questions, for example, your name, date of birth and confirm that you have removed all jewellery, underwear and make up etc.

You will be collected for theatre and taken to the theatre reception area where the nurse will check your details again, whilst this can appear repetitive it is all done to ensure your safety.

From theatre reception you will be taken to the anaesthetic room, a small room within the theatre complex. Here the anaesthetist will give you your anaesthetic medication, and once you are asleep you will be taken into theatre and surgery performed.

What is done during surgery varies with each individual and the structure of your spine. Remember the surgeon is dealing with structures that are different to normal, and although he/she is very experienced, they need to work with what they find inside you. This makes every case individual, and even though scans are very advanced, they still cannot show all the detail of the microscopic structures. The surgeon will see all the finer detail during your operation this makes you and your surgery unique.

There are still general themes to the recovery of everyone, which are discussed in the next few pages and this should help you understand what to expect.
Recovery Room

When your operation is over you will be taken to the recovery area, it is here that you will wake up from your anaesthetic, and the recovery staff will monitor you till you are awake enough to return to the ward. You will be in your own bed as you wake up and you will stay in this whilst in recovery and be transferred back to the ward in it, you will not need to be moved from or onto any bed or trolley.

No visitors are allowed in the recovery area, and you will usually only need to spend approximately one hour here before you will be transferred back to the ward.

You will have your blood pressure and pulse checked at regular intervals and the staff will check your leg movements and your wound. This can seem a bit repetitive but it is all done to ensure your safe recovery.

Back on the ward

Once the recovery staff are happy with your progress, and you have recovered enough from your anaesthetic, you will be transferred back to the ward.

You will wake up in recovery with most of the things mentioned below, as you improve we will reduce the number of things you have.

Until you are fully awake from the anaesthetic you will be given oxygen through a mask that goes over your nose and mouth. You will continue to have your blood pressure and pulse checked at regular intervals and your leg movements and wound. This is done less frequently after the first few hours once you return to the ward and as you get better it reduces to a few times a day.

Tethered cord can be complicated and can be present together with other abnormalities. The list that follows gives an explanation of some common associated abnormalities and terms that you may hear.

Spina bifida occulta

An abnormality present in the bones of the lower part of the spine present in 5-10% of the population. This only causes problems when there is an additional underlying abnormality as well.

Filum Terminale

This is a piece of tissue that works a bit like an elastic anchor for the spinal cord. It stretches as we move and bend, and brings the spinal cord back into the correct position when we straighten up again.

Thickened Filum

This is when the filum (see above) is thickened due to fatty or fibrous tissue. This makes it less like elastic and unable to give, so as the person moves it is the spinal cord and nerve roots that get stretched instead of the Filum terminale.

Dermoid or Epidermoid cyst

A benign tumour of skin cells

Lipoma or lipomyelomeningocele

Malformations in which a fatty lump under the skin develops in an abnormality of the lower spinal bones. The nerve roots, and filum terminale become embedded in the fatty lump, and therefore catch (tether) the spinal cord.
increase your tolerance to everyday activities, pace yourself and build it up slowly. Remember you have had surgery and this will make you feel tired causing sometimes the simplest of activities to be an effort, but this will improve as your recovery progresses.

You can undertake all the usual activities of daily life as you feel comfortable this includes walking, shopping, driving, sexual activity.

You can return to work as soon as you feel you can cope. Heavy lifting should only be performed in the correct way and should be avoided for the first three months.

You will be sent an outpatient appointment by post, to come to clinic so we can check you are recovering well, this is usually about 3 months after you have been discharged home.

If you have any queries at any time, before or after your surgery please do not hesitate to contact us or speak to your GP :-

Spinal Nurse Specialist - Keren Smallwood 0151 529 8853

Physiotherapist - 0151 529 5451

Secretary to your Consultant

You will have a drip in your hand so that you can be given fluids through this until you are awake and well enough to drink and eat. This drip tube can also be used, to give you pain killing medication (analgesia) to ensure that you are comfortable.

Some patients will have a PCA (patient controlled analgesia) this is a button that you control and you can press this when you want some pain killing medication. With each push of the button you give yourself a dose of painkiller (analgesia) through a small tube in your hand. This does have a safety override so that you cannot give yourself more than a set dose already programmed into the machine, regardless of how many times you press the button.

It is not unusual for you to need to stay lying flat in bed for approx 3-5 days after this type of surgery. This is to put less pressure on the internal repair of the linings the brain and spinal cord sit inside, and help to reduce the risk of a fluid leak from the wound in your back.

It is usual after this procedure to have a urinary catheter in place for a few days, it is inserted whilst you are asleep in the theatre. This is to drain all your urine into an external catheter bag for you. It also means that if you are unable to get out of bed for a few days you will not need to worry about using bedpans or bottles, but more importantly it allows the staff to monitor your fluid output.

Whilst you remain on bed rest the nursing staff will give you the help that you will need with washing and changing.

When you are drinking and eating well, your drip will be removed, and you will be encouraged to move around the bed. It is important that you do the physiotherapy exercises described in the Physiotherapy section of this booklet, to help prevent any problems occurring.
After a Few Days

Your surgeon will decide when he/she is happy for you to get out of bed, depending on your individual procedure and your recovery. When you are allowed to get up out of bed, then it is always better to have the head of your bed slowly lifted so that you do not feel dizzy. When you have been lying in bed for a few days your body needs to adjust to the changes required for you to be upright again, so if you get straight up you are likely to feel very dizzy and sick. However if you sit up gradually then your body can gently adjust itself to being upright again.

There is a physiotherapy team working on all the wards, and a physiotherapist will see you if you have any difficulties, once you are able to get out of bed. If needed they will check your walking and movement and give you advice on exercises. It is important that once you are out of bed that you gradually return to doing as much for yourself as you can. This is all part of your expected recovery and although it is difficult at first you will find that the more you are able to do the easier you are able to move and you will become more comfortable.

Once you are up and walking around we will be able to remove your catheter, this is easily done on the ward and is not painful. You will then be able to use the toilet. After removal of your catheter initially you will be expected to pass urine into a bedpan or urine bottle, which you can take to the toilet with you. This is so that the nursing staff can make sure that your bladder is working properly without the catheter.

Some patients will need to have a scan of their bladder. This involves using a small ultra sound machine, by your bed. We hold a small probe on the surface of your abdomen just below your belly button, and it can tell us how much urine you have in your bladder. If we do this after you have been to the toilet then we can tell if you have emptied your bladder properly and that it is working well.

Going Home

Once you are walking around the ward, are feeling better and the medical staff are happy with your wound healing you will be allowed to go home.

Medication will be organised for you to take home, however this can sometimes mean you need to wait till the evening on your discharge day. If you can arrange with your GP to have some already at home this will prevent you needing to wait.

It is possible to arrange a district nurse to check your wound and remove your stitches approximately a week after your surgery. This can mean waiting in your house all day so some patients prefer to go to their local GP surgery for the practice nurse to do this. If you would prefer to do this please let the ward staff know. If you feel you will be unable to go to your surgery then a date for the district nurse visit will be given to you before you leave the ward. Please make sure that if you are not going home to your usual address and you are going to stay with someone else you inform the staff, to ensure that the district nurse comes to the correct address.

If you need transport home it is advisable to let the staff know when you are admitted, so this can be arranged in advance. If you are travelling home by car, sit in the front passenger seat and recline the seat back to make you more comfortable whilst travelling.

The evidence shows that patients who return to a normal routine as quickly as possible make the best recovery. You should progressively return to your normal daily routine as quickly as possible. It is important that you do not go home and spend a lot of time lying down, as this can cause problems. It is better to spend time moving around your house, doing things in short sessions, then resting. Gradually