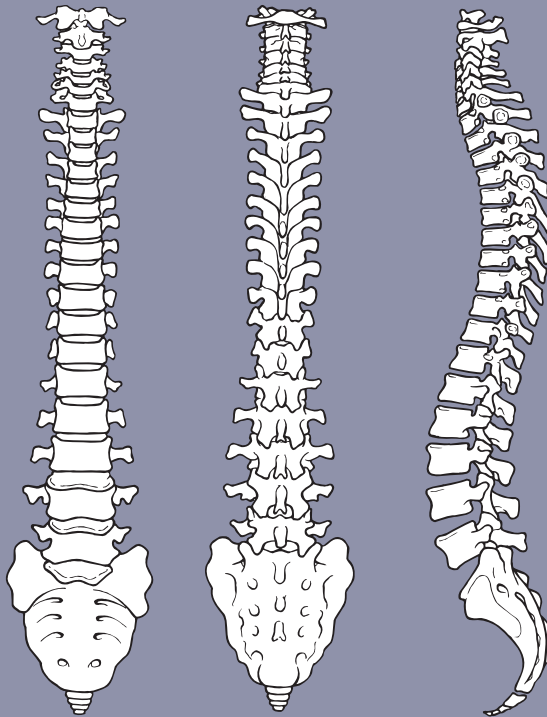




BASS

British Association of Spine Surgeons

Cauda Equina Syndrome



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Following your examination and MRI scan, you have been diagnosed with having or possibly developing, cauda equina syndrome. Cauda equina syndrome (CES) is a relatively rare but serious condition where the nerves travelling down the central spinal column of your lumbar spine (lower back), which control your legs, bladder, bowel and sexual function are compressed (squashed).

Cauda equina syndrome is a spinal emergency, affecting between 1 in 33,000 to 1 in 100,000 people. This represents just 2–6% of all lumbar disc problems which require surgery. It is a clinical diagnosis supported by the appearance of MRI scan images of cauda equina compression. Urgent clinical examination and radiological diagnosis (MRI or CT) is extremely important so as not to delay the surgical treatment. There is evidence that earlier surgery, is associated with better outcomes, particularly when symptoms are recent onset and progressive. Most surgeons would prefer to carry out surgery as soon as it is safe to do so.

The aim of spinal surgery is to preserve nerve function present at the time of surgery. Spinal surgery cannot fix any damage to the nerves themselves.

There is scope for improvement in nerve function, but this is **not** guaranteed. There is a good chance of helping the pain in the legs (sciatica) over time.

There is a small risk of making matters worse including:

- paralysis of the legs
- complete loss of bladder and or bowel function
- sexual difficulties, including inability to gain an erection or sexual feeling.

If the cauda equina is damaged before surgery, then an operation may not result in full recovery.

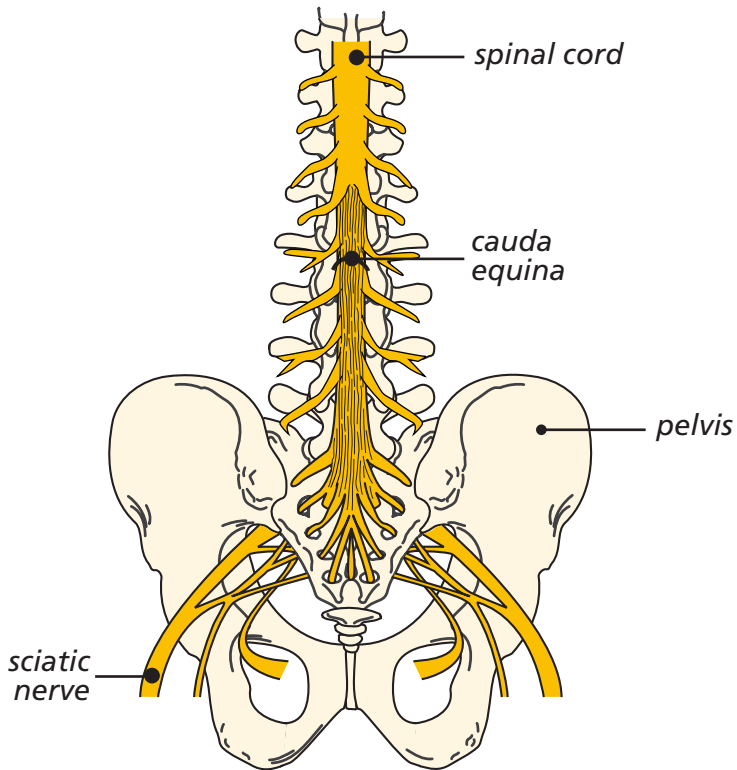
It is very difficult to predict how much recovery to expect, but generally, nerve recovery is slow.

Cauda equina syndrome can cause symptoms of:

- numbness/altered sensation in the buttocks, inner thighs, genital/saddle (bottom) area which is not normal for you
- pain in the lower back and legs, with or without leg weakness and numbness which is severe or getting worse
- sudden difficulty with bladder or bowel function, including loss of feeling and control (incontinence) or not being able to pass or have the urge to pass urine (retention) which is not normal for you
- loss of sexual function/feeling which is not normal for you, including (for men) an inability to achieve erections or ejaculation.

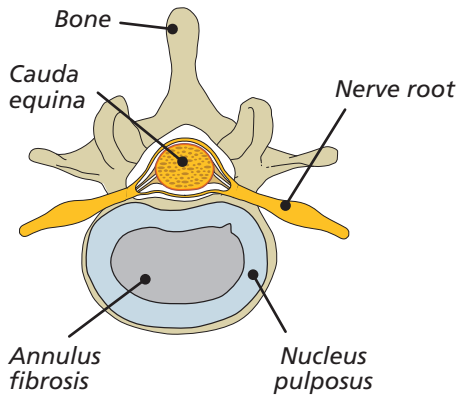
The normal spinal column has a central canal (or passage) through which the spinal nerves pass down. At each vertebral level, spinal nerve roots branch out to each side. The solid spinal cord stops at the top of the lumbar spine (lower back) and from this point the nerves to the bottom and legs pass through the lower canal like a horse's tail (cauda equina). The nerve roots and cauda equina are surrounded by cerebrospinal fluid (CSF) and are all contained within a membrane, or covering, called the dura mater, rather like the thin layer that covers a boiled egg. There are five bones (vertebra) in the lumbar spine. In between each bone is an intervertebral disc which acts as both a spacer and a shock absorber. The disc is composed of two parts: a soft gel-like middle (nucleus pulposus) surrounded by a tougher fibrous wall (annulus fibrosus).

Diagram showing the position of the cauda equina

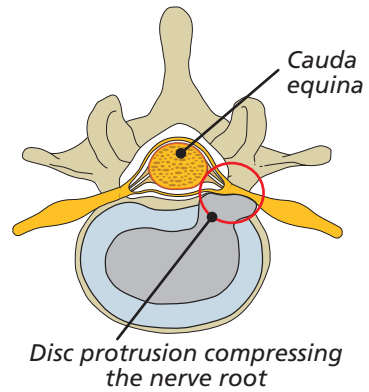


The commonest cause for cauda equina syndrome is an acute lumbar disc protrusion, involving a very large fragment of disc material which protrudes centrally into the spinal canal. This is a different situation, to when a lumbar disc protrudes and compresses on a nerve root(s), which branch out at the side of the spinal column and travels down to the corresponding leg(s). This could cause radicular pain, commonly known as sciatica and not cauda equina syndrome (see diagrams opposite).

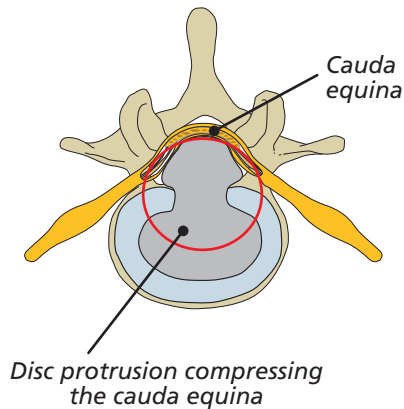
Overhead (axial) view of a normal lumbar disc



Lumbar disc protrusion with compression of the nerve root



Central lumbar disc protrusion with compression of the cauda equina



Other causes of cauda equina syndrome include:

- a more modest acute disc bulge, in the presence of severe spinal stenosis (narrowing of the central spinal canal) from degenerative changes such as facet joint arthritis
- a spinal tumour
- an infection, haemorrhage (bleed), cysts/fatty collections or inflammation in the spine
- severe spinal injury, such as a fracture, stabbing or gunshot incident

- a birth defect, such as an abnormality with the blood vessels (arteriovenous malformation – AVM).

In certain circumstances, such as in spinal stenosis, symptoms may come on more gradually and can often be mistaken for signs of simply 'getting older'.

Diagnosing cauda equina syndrome

Any patient experiencing the symptoms of CES should be assessed urgently. Usually this will be by an accident and emergency (A&E) doctor or GP. If a clinician suspects cauda equina syndrome then they will refer you to the appropriate pathway and specialist for further assessment and imaging as required. Diagnosis is confirmed following an examination and urgent MRI scan. In CES there may be a problem with the ability to feel a pin prick around the buttocks, genitals and/or back passage. The strength of the muscle which controls the back passage may also be reduced. It will therefore be necessary for the doctor to examine your back passage. An assessment of your strength, reflexes and sensation to your legs will be carried out.

Other tests may also be necessary, including a bladder scan to assess whether the bladder is retaining (holding) urine, immediately after going to the toilet. It is likely that if the scan reveals a large volume of urine (around 200mls or more) is being retained, or CES surgery is necessary, then a catheter will be inserted, to drain the urine from the bladder. This would remain in place until further assessment and/or surgical treatment has been performed.

If CES has been confirmed, urgent treatment and/or surgery will be necessary to relieve the pressure on the nerves and prevent permanent damage, such as paralysis of the legs, loss of bladder and bowel control and problems with sexual function. The treatment and/or surgery necessary, depends on what is causing CES. When the cause of cauda equina syndrome is a lumbar disc protrusion, urgent surgery is necessary.

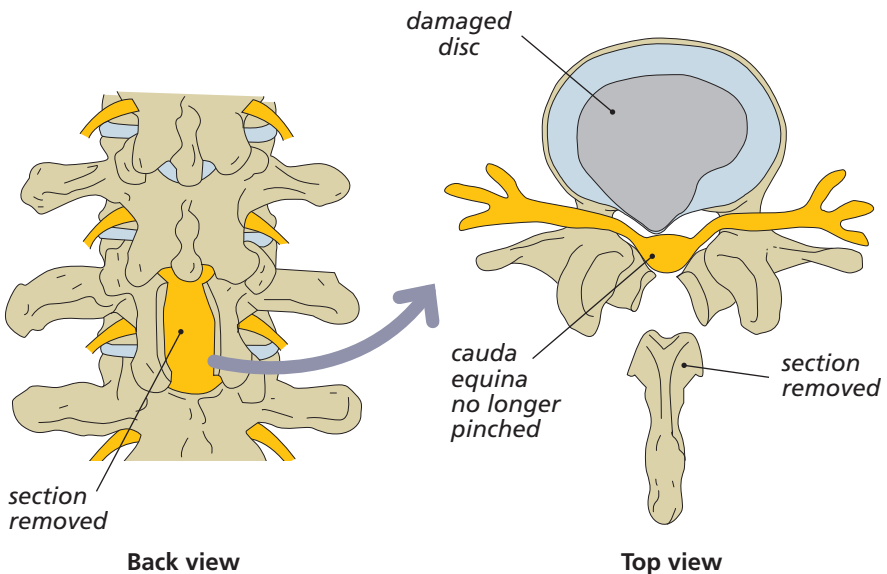
The operations most commonly performed for a lumbar disc protrusion causing CES is a discectomy/decompression through a **laminectomy** or a **laminotomy (bilateral / unilateral)**.

NB: Different operations may be required for the other causes of CES.

The operations

Laminectomy

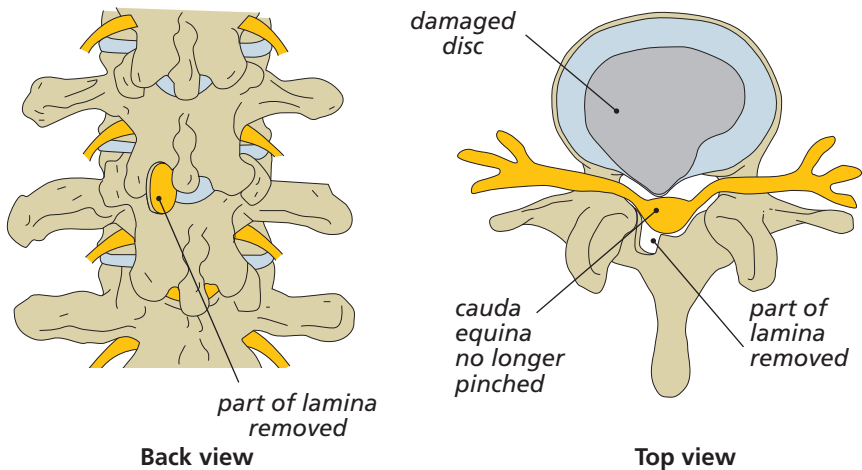
This is performed through an incision in the midline of the lower back. The muscles are held apart to gain access to the bony arch and roof of the spine (lamina). The surgeon needs to gain entry into the spinal canal by removing this bone and opening up the space surrounding the cauda equina. This allows a large enough window for the disc prolapse to be removed. The disc is entered, to remove any loose fragments of the disc material within it. A microscope is often used for this surgery, to give greater magnification of the structures.



View of the surgical removal of the lamina to get to the protruding disc material

Laminotomy (bilateral/unilateral)

This is performed through an incision in the midline of the lower back. The muscles are held apart to gain access to the bony arch and roof of the spine (lamina). Next, the surgeon needs to gain entry into the spinal canal by removing some bone, making a small window in the lamina (laminotomy) on one side (unilateral) or both sides (bilateral). This allows a large enough window for the disc prolapse to be removed. The disc is entered, to remove any loose fragments of the disc material within it. A microscope is often used for this surgery, to give greater magnification of the structures.



View of the surgical removal of one side of the lamina (unilateral laminotomy) to get to the protruding disc material

The nature of spinal surgery for CES is not a 'cure' but is aimed at providing the best chance for improvement and the return of nerve function. Sometimes however, numbness or weakness can persist, even with a technically successful operation. This will depend on

how much nerve damage has occurred beforehand. If permanent nerve damage has occurred, surgery cannot repair it. Recovery of function however, including bladder and bowel control, may continue to improve over a period of up to two years.

Risks and complications

As with any form of surgery, there are risks and complications associated with it. These include:

- damage to a nerve root. This occurs in less than one out of 100 cases of primary surgery but is much more common in revision or 're-do' surgeries where injury can occur in up to 10 out of 100 cases. If this happens, you may get weakness in the muscles supplied by that particular nerve root and / or numbness, tingling or hypersensitivity in the area of skin it supplies
- tearing of the outer lining or covering which surrounds the nerve roots (dura). This is reported in between 5–15% of primary surgery cases.. It may occur as a result of the bone being very stuck to the lining and tearing it as the bone is lifted off. Again, it is much more common in 're-do' surgery, up to 25% of cases. Usually, the hole or tear in the dura is repaired with stitches, a patch or a special glue. If the puncture or hole re-opens you may get cerebrospinal fluid (CSF) leaking from the wound, headaches or, very rarely, meningitis. Although rare, the problems of leakage can persist. This could result in you having to return to theatre to enable the surgeon to revise the repair of the dura but the risk of that operation being required within a few days or weeks is less than 0.05%
- recurrent or worsening leg pain(s). This can occur as a result of scarring or further disc protrusion, which is more common after CES surgery than for normal disc surgery, (occurring in more than five out of 100 cases at any time

from a few days to several years later)

- problems with positioning during the operation, which might include pressure problems, skin and nerve injuries, and eye complications including, very rarely, blindness. Special gel mattresses and operating tables are used to minimise this
- infection. Superficial wound infections may occur in up to four out of 100 cases. These are often easily treated with a course of antibiotics. Deep wound infections may occur in fewer than one out of 100 cases. These can be more difficult to treat with antibiotics alone and sometimes patients require more surgery to clean out the infected tissue. This risk may increase for people who have diabetes, impaired immune systems or are taking steroids
- bleeding. The reported risk of a vascular injury during disc surgery is 1 in 4,000 cases. You must inform your consultant if you are taking tablets used to 'thin the blood', such as warfarin, aspirin, rivaroxaban or clopidogrel. It is likely you will need to stop taking them, as they increase the risk of bleeding. Taking medication like non-steroidal anti-inflammatories (NSAIDs) could also increase your risk of bleeding and your surgeon will stop you taking these before your operation as well.
As surgery is likely be scheduled as soon as possible, it may be necessary to give you medication to reverse the effects of certain 'blood thinners' you may have been taking
- blood clots (thromboses) in the deep veins of the legs (DVT) or lungs (PE). These occur when the blood in the large veins of the leg forms blood clots and may cause the leg to swell and become painful and warm to the touch. Although rare, if not treated this could be a fatal condition if the blood clot travels from the leg to the lungs, cutting off the blood supply to a portion of the lung. It is reported as happening in fewer than one out of 700 cases. There are many ways to reduce the risk of a blood clot forming. The most effective is to get moving as soon as possible after your operation. Walk regularly as soon as you are able to, both in hospital

and when you return home. Perform the leg exercises as shown to you by the physiotherapist and keep well hydrated by drinking plenty of water. Ladies are also advised to stop taking any medication which contains the hormone oestrogen immediately (like the combined contraceptive pill or HRT) and for four weeks after surgery, as taking this during spinal surgery can increase the chances of developing a blood clot. If you are experiencing persistent leg weakness and are not able to be up and about within a few days after the surgery, then you may require daily injections of a 'blood thinner' to lower your risk of developing a DVT.

There are also very rare but serious complications that in extreme circumstances might include:

- further damage to the cauda equina resulting in paralysis (the loss of use of the legs, loss of sensation and loss of control of the bladder and bowel and sexual function). This can occur through bleeding into the spinal canal after surgery (a haematoma). If an event of this nature were to occur, every effort would be made to reverse the situation by returning to theatre to wash out the haematoma. Sometimes, however, paralysis can occur as a result of damage or reduction of the blood supply to the nerves and this is, unfortunately, not reversible
- stroke, heart attack or other medical or anaesthetic problems. The risk may be greater in those people who already have existing medical health conditions

- extremely rarely, death; as a result of damage to major blood vessels or vital organs at the front of the spine, which is reported as happening in one out of 10,000 cases; or general anaesthetic fatal complications which have been reported in one out of 250,000 cases.

What to expect after surgery and going home

Immediately after the operation you will be taken on your bed to the recovery ward where nurses will regularly monitor your blood pressure and pulse. Oxygen will be given to you through a facemask for a period of time to help you recover from the anaesthetic. You will have an intravenous drip until you are able to drink adequately.

A drain (tube) may be placed near the surgical incision if there has been significant bleeding during the operation. This removes any excess blood or fluid collecting under the wound. The drain will be removed when the drainage has stopped, usually the next day, after surgery.

It is very normal to experience some level of back and leg pain after the surgery. The nursing and medical staff will help you to control this with appropriate medication. The symptoms in your legs may fluctuate due to increased swelling around the nerves. As the nerves become less irritated and swollen, the leg pains should begin to settle. This can still take 8–12 weeks, or longer. However, everyone is different, some people notice an immediate improvement in some or all of their symptoms, particularly the leg pains while others who have experienced severe nerve damage, may still have tingling or numbness in their legs. These symptoms can improve over time but nerves can take a long time to recover (18 months–2 years). It is important not to suddenly stop taking certain pain relief medication, such as morphine or neuropathic medication (gabapentin, pregabalin or amitriptyline). It will be necessary to gradually 'wean' yourself off them – your GP can advise you if necessary.

It is likely that other CES symptoms, like bladder or bowel problems, will remain immediately after surgery. Bladder problems are initially dealt with by inserting a urinary catheter to drain the urine and leaving it there, but after surgery your nurse will carry out a 'trial without catheter' (TWOC) test to assess your bladder function. If not fully recovered, it may be necessary to teach you how to catheterise yourself 3–4 times a day to empty your bladder. This is called 'intermittent self-catheterisation' (ISC). If you have ongoing issues with the function of your bladder and/or bowels, then you will be reviewed by a specialist nurse prior to your discharge and appropriate follow up will be arranged.

A physiotherapist may visit you after the operation to assess your muscle strength and teach you exercises that can help you overcome any balance issues you have because of muscle weakness or poor sensation. The weakness in your legs can improve over time, as the nerves affected recover and it may be possible to build up the muscles around to compensate for those weaker ones, which the physiotherapist can also help you with. When possible, they will help you out of bed and show you the correct way to move safely. Once you are confident and safely mobile, you will be encouraged to practise climbing stairs with the physiotherapist, if this is appropriate. Once you are safe enough to manage at home you will be discharged.

Please arrange for a friend or relative to collect you, as driving yourself or taking public transport is not advised in the initial stages of recovery. If you qualify for patient transport and are likely to require this service, please let one of the nurses know as soon as you can, as this may need to be pre-arranged. Your discharge home could be delayed if not.

A small number of patients need formal neurological rehabilitation and physiotherapy in a spinal injuries' unit before going home.

Wound closure

Skin wound closure depends on your surgeon's preference, and include absorbable sutures (stitches), removable sutures or clips (surgical staples).

If you have removable sutures or clips, you will be advised by the ward nurse to arrange an appointment with your GP's practice nurse, usually 10–14 days after the operation, for them to be removed.

If you have absorbable sutures, you will be advised by the ward nurse whether you need to make an appointment with your GP's practice nurse to have a wound check or when you can take off the dressing yourself.

You may shower 48 hours after surgery if you are careful but you must avoid getting the dressing too wet. Most dressings used are 'splash-proof', but if water gets underneath, it will need to be changed. A simple, dry dressing from a pharmacy is sufficient to use. Bathing should be avoided for two weeks.

Please contact your hospital or your GP if you think your wound might be infected. Symptoms could include:

- redness around the wound
- wound leakage
- you have a high temperature.

Once the wound has been checked and if the scar is sensitive to touch, you can start to massage around the scar using an unperfumed cream or oil to encourage normal sensation and healing.

Recreational activities

It is important to keep as mobile as you can after surgery. You will find you get stiff if sitting for longer than about 20 minutes, so get up and walk about regularly. Walking outside is fine but again, increase your walking distances gradually. The fibrous wall of the disc cannot be repaired during surgery and will heal at different times for everybody, so you will be advised to avoid lifting anything heavy, certainly for the first 2–3 weeks, but maybe for as long as three months, after your operation. Having surgery does not prevent you from developing further disc degeneration.

Excess body weight will increase the load and pressure on the intervertebral discs and may exacerbate any structural problems. This could increase the potential for further disc prolapses occurring later on. Losing weight may be beneficial if a patient is obese.

Please check with your consultant and physiotherapist when you are able to resume specific activities, such as swimming or running, as the advice could range from between six weeks to three months. A gradual return to sport is then advisable. Your surgeon may advise you to avoid flying for six weeks (and long-haul flights for up to three months), because of the increased risk of deep vein thrombosis after the surgery.

Bladder, bowel and sexual function

The nerves to the bladder, bowels and genital/saddle (bottom) area will take time to recover. In some cases, the nerves may be permanently damaged, even though surgery has completely taken the pressure off them. Only time will tell how much they will recover. During this time, you may experience some difficulty with:

- passing or controlling urine
- passing or controlling stools (poo)
- controlling flatus ('wind')
- a numb sensation in the saddle (bottom) area
- for women, reduced sexual sensation
- for men, difficulty achieving erections and ejaculation.

It is important that bladder problems, such as being unable to empty your bladder, are managed properly, to avoid chronic bladder infections and potential kidney damage. You should discuss any concerns with your nurse or doctor, in particular:

- repeated urine infections
- if you feel that you have not completely emptied your bladder or bowel
- if you need to empty your bladder or bowel unusually often
- you are leaking urine or faeces (poo).

If you are experiencing the loss of bladder or bowel function, the following tips may be helpful:

- passing a catheter to completely empty your bladder 3–4 times a day (you will be shown how to safely do this by a qualified person beforehand)
- drinking plenty of fluids and ensure good personal hygiene to prevent urine/kidney infections

- with a gloved hand, check your bowels for faeces (poo) and manually remove it. (You will be shown how to safely do this by a qualified person beforehand). You may need to use suppositories or enemas to soften the stools first
- wear protective pads and pants to prevent leaks and unnecessary embarrassment.

A small number of patients with ongoing problems may need further help and assessment by their local continence department, which may include colorectal and urological services, or in a spinal injuries unit.

People often avoid talking about issues of this nature or problems with their sexual function but please don't be embarrassed to ask for help. Proper advice can help avoid the potential health risks of cauda equina syndrome and help make living with the condition more manageable.

Once you are at home, if you do feel that you need further help, most areas offer a service for advice and treatment in sexual and continence problems. You can often telephone your local continence service to refer yourself, without having to go through your GP.

Driving

Driving is permissible after recovery from surgery and if you feel safe. You do not need permission from a doctor to drive. You must tell the DVLA that you have a spinal injury. You could be fined £1000 if you don't and may be prosecuted if you're involved in an accident as a result. If you have no altered sensation or weakness in your legs, you may resume driving when you feel safe to do so, but you must be confident to do an emergency stop. For most patients this will be 4–6 weeks after surgery. It is advisable not to travel for long distances initially (no longer than 20 minutes), without taking a break to 'stretch your legs'. Gradually increase your sitting tolerance over 4–6 weeks.

Work

Returning to work is dependent both on your recovery and your job. Patients who have made a full recovery after cauda equina syndrome, may be off work for four weeks but if in a strenuous job, may need up to take up to eight weeks off. It is always sensible to discuss with your employer if you can return on 'light duties' or reduced hours at first. There is usually nothing to stop you doing computer/office work at an earlier date, as long as you can keep moving about. The hospital will issue you with a fitness to work (off work) certificate or you may ask your GP.

People with more extensive damage beforehand and those whose recovery and expectations for improvement are less should check with their consultant.

Follow-up

Your surgeon will advise you when you should attend clinic after your operation. If you have any queries before your follow-up date do, please contact the nurse specialist or other member of your consultant's team.

If you have any questions regarding the information in this booklet, please do discuss them with either the ward nurses or a member of your consultant's team.

Living with cauda equina

Coping with long-term problems following cauda equina syndrome can be very difficult and isolating, so it can be very helpful to have the support from others who really understand what you are going through. Joining a cauda equina support group can be a really good idea.

You may find the information on the website **caudaequinauk.org.uk** helpful. It includes patients' own experiences of living with cauda equina.

Further help and support

The Pain Toolkit

Web: www.pain toolkit.org

The Pain Toolkit helps people all over the world self-manage persistent pain.

Incontinence UK

Web: www.incontinenceuk.co.uk

Tel: 0800 068 3625

Incontinence UK is one of the leading suppliers of incontinence products, including a range of incontinence pants & pads.

Bladder & Bowel Community

Web: www.bladderandbowel.org/help-information/free-radar-key-home-delivery-service

Tel: 0800 031 5406

Having a RADAR key and a 'just can't wait' card, allows you to unlock and access useable and clean toilet facilities.

Mind

Web: www.mind.org.uk

Tel: 0300 123 3393

Mind is a charity who:

- strive to make mental health services more human
- work alongside people to help them realise their potential
- raise awareness, promote understanding and challenge stigma
- value the importance of community and the benefits of mutual support.

Samaritans

Web: www.samaritans.org/how-we-can-help-you

Tel: 116 123

Samaritans offer a safe place for you to talk any time you like, in your own way – about whatever is getting to you. You do not have to be suicidal.

Spinal Injuries Association

Web: www.spinal.co.uk

Tel: 0800 980 0501

The Spinal Injuries Association offer a range of services that support everyone who need to access expert information, advice and support when they need it most.

Back Up Trust

Web: www.backuptrust.org.uk

Tel: 0208 875 1805

The Back Up charity has a vision where all people with spinal cord injury can reach their full potential. Their mission is to deliver services that build confidence, independence and inspire people affected by spinal cord injury to transform their lives.

The Department of Work and Pensions

Web: www.dwp.gov.uk

Support and guidance related to a range of working age, disability and ill health benefits.

Turn 2 Us

Web: www.turn2us.org.uk

A national charity that helps people in financial hardship gain access to welfare benefits, charitable grants and support services.

Citizen's Advice

Web: www.citizensadvice.org.uk

Tel: 03444 111 444

Citizen's Advice provides free, confidential and independent advice to help people overcome their problems. They value diversity, champion equality and challenge discrimination.

UK Government

Web: www.gov.uk/browse/disabilities

The best place to find information about government services and information related to benefit entitlement.

Relate

Web: www.relate.org.uk

Tel: 0300 100 1234

The UK's largest provider of relationship support.

Lose Weight – Better Health

Web: www.nhs.uk/better-health/lose-weight/

Free health programmes offering lots of help and support to lose weight.



What is the British Spine Registry (BSR)?

The British Spine Registry aims to collect information about spinal surgery across the UK. This will help us to find out which spinal operations are the most effective and in which patients they work best. This should improve patient care in the future.

The Registry will enable patient outcomes to be assessed using questionnaires. These will allow surgeons to see how much improvement there has been from treatment.

This has worked for hip and knee joint replacements through the National Joint Registry. We need your help to improve spinal surgery in the UK.

What data is collected?

Your personal details allow the BSR to link you to the surgery you have had. They also allow us to link together all the questionnaires you complete. If you need any further spinal surgery in the future, details of previous operations will be available to your surgeon.

Personal details needed by the BSR are your name, gender, date of birth, address, email address and NHS number.

Your personal details are treated as confidential at all times and will be kept secure. This data is controlled by the British Association of Spine Surgeons (BASS) and held outside the NHS. Personal details will be removed before any data analysis is performed, retaining only age and gender. Your personal data and email address will not be available to anyone outside BASS and its secure IT provider. Anonymised data may be released to

approved organisations for approved purposes, but a signed agreement will restrict what they can do with the data so patient confidentiality is protected.

Your personal data is very important, as this will allow us to link details of your diagnosis and surgery with any problems or complications after surgery. You may also be asked to complete questionnaires before and after surgery to work out how successful the surgery has been. This will only be possible if we can connect you to the questionnaires through your personal details.

Do I have to give consent?

No, your participation in the BSR is voluntary and whether you consent or not, your medical care will be the same. Your personal details cannot be kept without your consent. This will be obtained either by asking you to physically sign a consent form or electronically sign one through an email link to a questionnaire or at a questionnaire kiosk in the outpatient clinic.

You can withdraw your consent at any time or request access to your data by:

- going to the patient section of the BSR website at www.britishspineregistry.com; or
- writing to us at the BSR centre (see address on next page). Please state if you are happy for us to keep existing data but do not want to be contacted, or whether you want your data to be anonymised (so it cannot be identified).

Research

Your consent will allow the BSR to examine details of your diagnosis, surgical procedure, any complications, your outcome after surgery and your questionnaires. These are known as 'service evaluations' or 'audits'.

Operation and patient information, including questionnaires in the BSR, may be used for medical research. The purpose of this research is to improve our understanding and treatment

of spinal problems. The majority of our research uses only anonymised information which means it is impossible to identify individuals. From time to time, researchers may wish to gather additional information. In these cases we would seek your approval before disclosing your contact details. You do not have to take part in any research study you are invited to take part in and saying no does not affect the care you receive.

All studies using data from the Registry will be recorded on the BSR website at www.britishspineregistry.com

Children

Parents are asked to consent for data to be collected from their child. Looking at the outcome of spinal surgical procedures is just as vital in children as it is in adults.

Further information

The BSR website at www.britishspineregistry.com contains more information, including details of any studies and any information obtained through the Registry data.

To contact the BSR, write to:

The British Spine Registry
Amplitude Clinical Services
2nd Floor
Orchard House
Victoria Square
Droitwich
Worcestershire
WR9 8QT

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