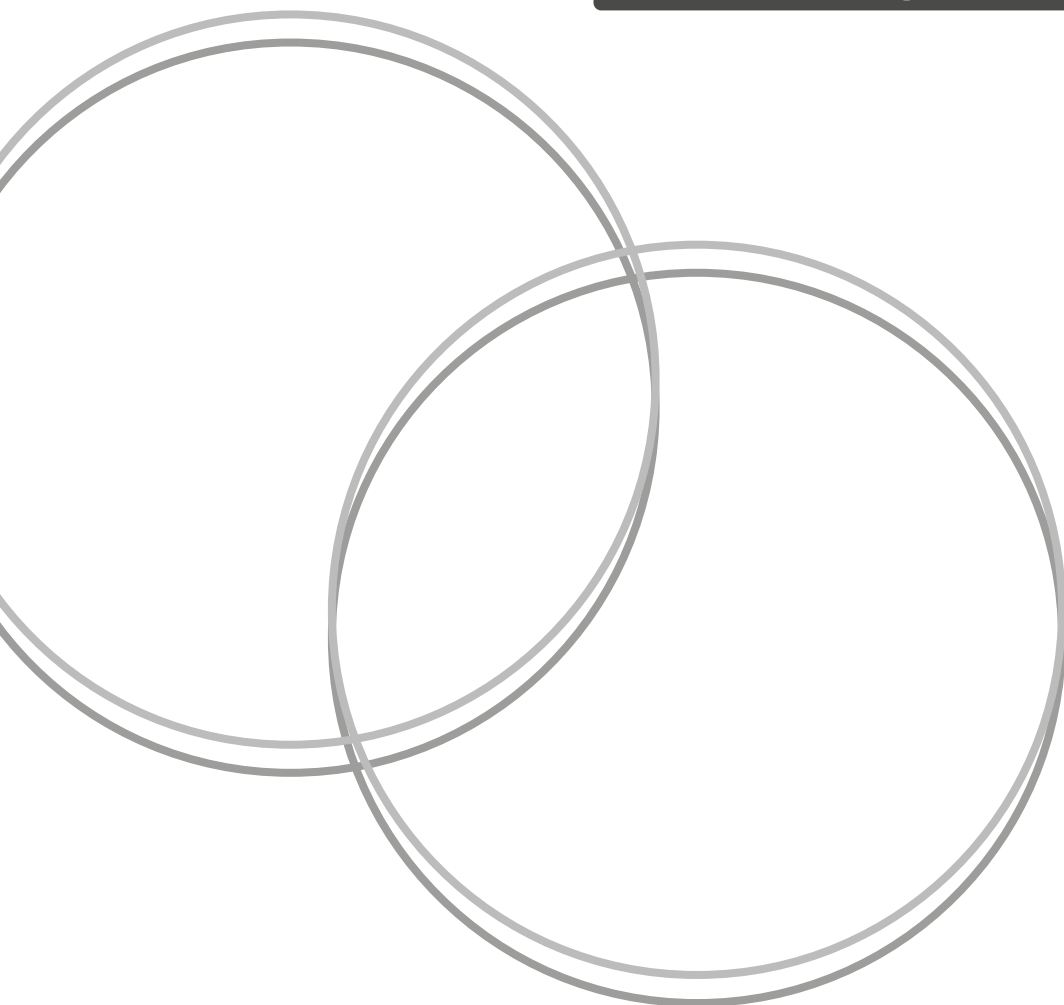


Cauda Equina Syndrome Awareness

Information for patients



You have been given this booklet because your healthcare professional has identified that you may be at risk of developing cauda equina syndrome. You have been advised to look out for symptoms which may be related to this.

Cauda Equina Syndrome CES is a rare but serious complication of spinal disorders, which needs immediate emergency medical assessment and treatment.

It is very important that you read and understand this information.

This booklet describes:

- what Cauda Equina Syndrome is
- when to seek emergency medical help

What is Cauda Equina Syndrome?

Cauda Equina Syndrome is a condition which can occur when the nerves of the Cauda Equina are compressed.

What is the Cauda Equina?

The spinal cord extends from the brain down through a canal inside the vertebral column. The spinal cord finishes just above your waist. In the spinal canal below the cord are a group of individual nerves, called the Cauda Equina. The nerves of the Cauda Equina supply the muscles that control the bladder, bowel and the muscles in the legs. It also supplies the sensation to the skin around the bottom, back passage, genitals and inner thigh.

What are the causes of Cauda Equina Syndrome?

Back pain is common. Nerve pain in the legs, which we sometimes call sciatica, is less common. Cauda Equina Syndrome, CES, is very rare, affecting 1 to 3 in 100,000 people. If it occurs it is usually in adults of working age, who develop back problems, and/or pain in one or both legs.

The most common cause of CES is a sudden large disc prolapse. If people have a narrow spinal canal then a moderate disc prolapse can cause CES. Less common causes include tumour, infection, or trauma.

If you suddenly develop sciatic pain in both legs, then you may be at greater risk of developing CES.

What are the main symptoms of Cauda Equina Syndrome?

If you have back and leg pain that has progressed to pain in both legs, this may be a warning symptom that CES may occur.

If you have back and leg pain with a recent onset of disturbance of your bladder or bowel function, sexual dysfunction or saddle sensory disturbance, then this also may indicate CES. We would define recent onset as any time up to two weeks.

Most commonly these symptoms develop suddenly and may worsen rapidly, within hours or days. However, some people develop symptoms gradually.

Saddle Anaesthesia

- Loss of feeling in or around the back passage, genitals, buttocks, and/or inner thighs.
- Altered feeling when using toilet paper to wipe yourself.

Bladder disturbance

- Difficulty starting the flow of urine.
- Difficulty when you try to stop or control your flow of urine.
- Not knowing when your bladder is either full or empty.
- Leaking of urine or recent need to use pads.
- Loss of sensation when you pass urine.

Bowel disturbance

- Loss of sensation when you pass a bowel motion.
- Inability to stop a bowel movement or leaking.

Sexual problems

- Change in ability to achieve an erection or ejaculate.
- Loss of sensation in genitals during sexual intercourse.

Weakness may affect part of your leg or foot.

- Severe or worsening strength in both legs – such as difficulty pulling the foot upwards, or straightening the leg.

If you have sciatica and develop symptoms suggestive of CES it is important for you to seek emergency medical help.

Bladder and bowel symptoms unrelated to CES

Both bladder and bowel problems are common in adults with or without back pain.

The problem may be unrelated or may have been present before the flare up of your back pain. For example:

- Many women leak urine when they cough or sneeze due to weakness of the pelvic floor.
- Men may have prostate problems.
- Some people have an irritable bladder or bowel and go to the toilet frequently.
- Some people get urine infections from time to time.

When back problems flare up, your bladder and bowel can also be affected by:

- anxiety
- severe pain
- medication: for example
 - drugs for nerve pain may cause you to pass water more or less frequently. For example, Amitriptyline and Gabapentin
 - drugs with codeine can cause constipation. Constipation can then cause bladder frequency.
- Widespread pain: pain which affects many muscles and joints.

What can you do to help yourself?

If the clinician does not ask about changes to your bladder, bowel, or feeling around the back passage & genitals then it is important to tell them about any symptoms you have.

Although this may feel embarrassing, be reassured that healthcare professionals will treat your condition with sensitivity and tact.

Timing is critical. The longer the pressure is on the nerves the more damage occurs. If it is unrecognised or treatment is delayed, then this may result in permanent loss of bladder and bowel function, loss of sexual function, and lower limb paralysis. If treated before the symptoms become severe, then the risk of permanent disability is reduced.

The most important thing you can do, if you suspect CES, is to go to an emergency service and be assessed by a clinician. Locally, we would recommend attending **Accident and Emergency at the John Radcliffe Hospital.**

Keep a record of:

- **The time that the bladder symptoms started**
- **The time if your symptoms progress or change.**

How is Cauda Equina Syndrome diagnosed?

Examination

Initially CES is suspected from the information that you tell the clinician.

If suspicious the clinician will do an assessment which may include:

- testing the feeling in your legs and the saddle region (back passage and genitals)
- testing the reflexes in the legs
- testing the strength of the muscles in the legs
- testing the tone and strength of the back passage muscle
- sometimes they will do an ultrasound of your bladder to see how much you can empty it

Important:

The clinician should always offer for a chaperone to be present when doing tests in the saddle region.

Investigations

CES can only be confirmed or excluded by a spinal MRI scan. It is important that this is done as an emergency. If for any reason you cannot have an MRI the clinician will arrange another type of scan.

The scan will show whether the nerves of the Cauda Equina are under pressure. If they are and you have symptoms suggestive of CES then the diagnosis of Cauda Equina Syndrome will be confirmed.

The MRI scan and examination findings will help the health care professional plan appropriate treatment and decide how urgently the problem needs treatment.

Thankfully in 9 out of 10 people with symptoms, CES is excluded. In this case the Health Care Professional will reassure you and advise you and your doctor of further treatment for your Back Pain problems. The best treatments for back problems are outlined in the NICE guidelines www.nice.org.uk/guidance/ng59.

How is Cauda Equina Syndrome treated?

The sooner the better

If CES is confirmed on MRI, the spinal surgeon will arrange for you to have an operation as soon as it is safe to do so.

There is evidence that earlier surgery is associated with better outcomes, especially if within 24 hours of the symptoms starting.

Making decisions together

If spinal surgery is offered the spinal surgeon will explain:

- The aim of spinal surgery is to preserve nerve function, present at the time of surgery.
- 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.
- 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.

If you are in any doubt, please discuss this leaflet with any health professional that is involved in your spinal care.

We hope this information answers your questions. If you need further information, please ask your healthcare team. They will be happy to help.

Your opinions and views are important to us. Please ask us about the NHS Friends and Family Test which gives you the opportunity to tell us what we did well and what we can do to improve. You can also have an informal conversation at any point if there is something you would like to ask or tell us about.

www.ouh.nhs.uk/patient-guide/feedback/friends-and-family-test.aspx

Contact details

Oxford Spinal Surgery Unit

Nuffield Orthopaedic Centre
Windmill Road
Headington
Oxford OX3 7HE

Telephone: **01865 737 877**

Website: www.ouh.nhs.uk/spinal/

Email: spine.noc@nhs.net

Physiotherapy Department

Nuffield Orthopaedic Centre
Windmill Road
Headington
Oxford OX3 7HE

Telephone: **01865 738126**

Neurosciences

Neurosciences Ward

Level 2

West Wing
John Radcliffe Hospital
Headley Way
Headington
Oxford OX3 9DU

Telephone: **01865 234838**

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

Author: Alison West - Spinal Physiotherapist
April 2023
Review: April 2026
Oxford University Hospitals NHS Foundation Trust
www.ouh.nhs.uk/information



Making a difference across our hospitals

charity@ouh.nhs.uk | 01865 743 444 | hospitalcharity.co.uk

OXFORD HOSPITALS CHARITY (REGISTERED CHARITY NUMBER 1175809)

