

## UNDERSTANDING CAUDA EQUINA SYNDROME (UCES) STUDY SUMMARY

### What was the study?

Cauda equina syndrome (CES) occurs when the nerve roots in the lower spine are compressed. This can cause a range of symptoms such as pain, numbness, leg weakness and bladder, bowel, or sexual dysfunction. This usually happens due to a disc prolapse (when part of the soft joint between the bones of the spine wears out and moves). We collected information about the symptoms that people with CES experience, their current management, and what happens after discharge from hospital.

### When and where did the study take place?

The study took place between June 2018 and May 2020 in neurosurgery and orthopaedic spine departments in the United Kingdom (UK) in National Health Service (NHS) hospitals.

### Why was the research needed?

This study aimed to find out what symptoms people with CES have, how they are managed and how they recover to help plan treatment and services in the future.

### What were the questions studied?

- What sort of symptoms do people with CES have?
- How are people with CES investigated and treated?
- What happens to people with CES during the year after discharge from hospital?
- Is recovery related to symptoms or management?

### Who took part in the study?

There were 621 people with CES due to a disc prolapse between June 2018 and May 2019 who took part in the study. Questionnaires were filled in by 284 people with CES during the year after their surgery.

### How were patients and the public involved?

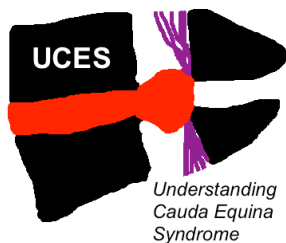
Patients at NHS Lothian with CES were involved with designing the study and the questionnaires. Patients across the UK provided feedback about the questionnaires and suggestions to improve the study.

### What were the results of the study?

Most people with CES had back pain, leg pain, and bladder problems. Fewer people had bowel problems or sexual problems. Around 1 in 3 people needed a bladder catheter to drain their bladder before surgery. People with CES reported that their symptoms had been present for longer than the health care professionals reported.

All people with CES had surgery. Surgery happened within a day of admission to the spinal ward in 99%. Surgery happened within 48 hours of when the symptoms started in around 1 in 3 people. Most people stayed in hospital between 2–5 days.





People with CES reported improved pain, mobility and disability after surgery compared to before surgery. At one year after surgery, half of people in the study still had bladder problems, bowel problems, and sexual problems. Around 1 in 10 people needed a catheter to manage their bladder after surgery. Two thirds of people needed an appointment with another health care professional as well as the spine surgeon during the year after discharge.

Needing a catheter after surgery was more likely in people who needed a catheter before the operation. More disability after surgery was associated with more disability before surgery. We did not find that the amount of compression on imaging, or the time between the start of symptoms and surgery made a difference to whether a catheter was needed or the amount of disability. However, most people had surgery straight after admission, and those with a catheter had surgery earlier than those who didn't need a catheter.

### **How has this study helped patients and researchers?**

This study shows that half of people with CES have problems during the year after surgery, and they need support with mobility, pain, bladder, bowel, and sexual function. This highlights the need for better rehabilitation services. People with worse symptoms before surgery tended to do worse, but many people with a catheter before the operation did not need a catheter after the operation. The proportions found in this study will help healthcare professionals talk to people with CES about their chances of recovery, and plan post-operative care and support for them. We did not find that those with quicker surgery or surgery within a certain time period did better. This information might be useful for planning investigations and surgery so that the best care happens in the best way at the best time for people with CES.

### **What further research is planned?**

We know that people continue to change after one year following surgery. We would like to find out how people are getting on at five and ten years after surgery. We also plan to look at some of the information already collected in more detail.

### **Who carried out the study?**

The study was sponsored by NHS Lothian in Edinburgh. Study stationery and materials were paid for by the Department of Clinical Neurosciences Endowment Fund at NHS Lothian. The study database was provided free of charge by Castor EDC. The study was supported by the British Neurosurgical Trainee Research Collaboration (BNTRC), the British Association of Spine Surgeons (BASS), and the British Orthopaedic Trainees Association (BOTA). The study was registered at ISRCTN (number: 16828522).

### **How can I find out more about the study?**

The study results are published, and are freely available to everyone online here:  
[https://www.thelancet.com/journals/lanep/article/PIIS2666-7762\(22\)00241-1/fulltext](https://www.thelancet.com/journals/lanep/article/PIIS2666-7762(22)00241-1/fulltext)

If you have questions about your own recovery, please talk to your GP or your local spine surgeon (orthopaedic surgeon or neurosurgeon).

If you would like to find out more about the study, you can contact the researchers leading the study via: [julie.woodfield@ed.ac.uk](mailto:julie.woodfield@ed.ac.uk)

