

## About CESA

CESA was founded in 2012 by CES sufferer Claire Thornber. Claire's life was devastated in 2010 when she suffered permanent neurological damage following a prolapsed disc. As a result of her treatment and the lack of support she experienced she recognised the need for a dedicated patient support group. She now dedicates her time to the cauda equina syndrome association and lives in the north west of England with her family.

"Having this safe haven where support is unconditional and nothing we are going through is off limits has helped me to feel like I can get through this (fully healed or not). Whilst it is terrifying to go through, knowing we are not alone is comforting".

**Amy**

"I would like to thank the CESA for presenting at The College of Paramedics & Yorkshire Ambulance Service Best Practice event. Having CESA attend our event raised the awareness of CES amongst frontline ambulance clinicians and contributed to the professional development of paramedics. This will certainly improve paramedics' ability to flag up potential CES at a much earlier point in time than before. The CESA presentation was particularly well received by paramedics due to the patient perspective element, real patients with real stories to tell was certainly a very powerful approach and got the message out loud and clear. I would like to support the CESA going forward to continue to raise awareness of this spinal emergency amongst paramedics".

**Yorkshire Ambulance Service**



## Support for people living with Cauda Equina syndrome

[www.ihavecaudaequina.com](http://www.ihavecaudaequina.com)  
0333 5 777 113



This leaflet has been produced with the help of JMW Solicitors, leading specialists in Cauda Equina Syndrome cases and a supporter of CESA. [www.jmw.co.uk](http://www.jmw.co.uk)



With thanks to Coloplast for the ongoing support. [www.coloplast.co.uk](http://www.coloplast.co.uk)



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## Welcome to the Cauda Equina Syndrome Association

The Cauda Equina Syndrome Association (CESA) is a patient led non-profit organisation, striving to raise awareness of cauda equina syndrome and support people living with the condition. We have a range of leading experts associated with the organisation who bring a wealth of knowledge and experience.

We aim to embrace people living with CES and by using our collective voice we hope we will bring about change and an end to unnecessary suffering. With the help of our members, we hope to reduce the number of people suffering from CES and empower and support people to continue to live positive, happy lives.

### What is Cauda Equina Syndrome?

Cauda equina syndrome (CES) is a serious spinal condition that causes bowel and bladder dysfunction and incontinence, permanent pain, loss of sensation or altered sensation in the saddle area, groin and legs and loss of sexual function. Every patient will experience these symptoms differently and they can vary in severity, as can the level of disruption to their life.

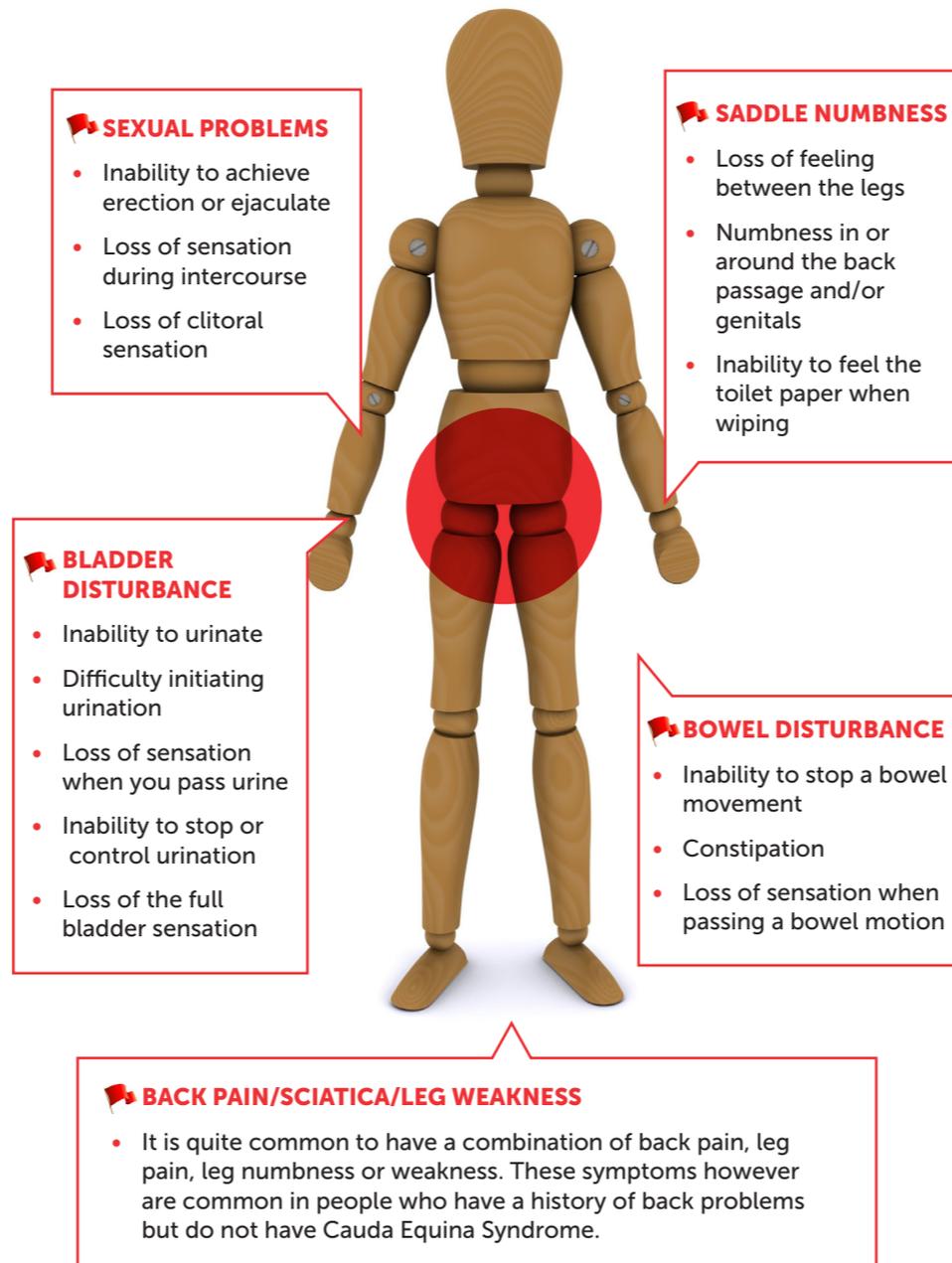
CES is caused when pressure is placed on the cauda equina nerves at the base of the spine, affecting how they function. This can be due to a prolapsed disc, tumour or a traumatic injury and can cause damage to the nerves. There is a 24-48 hour window from when the 'red flag' signs appear to operate and successfully relieve the pressure before permanent damage is caused.

### 'Red flags'

Opposite are warning signs that a person is developing cauda equina syndrome and requires urgent investigations and surgery.

### 'Red flag' awareness

Most people have never heard of CES unless they are unlucky enough to be affected by it therefore the 'red flag' signs are relatively unknown. However raising awareness of the first signs is absolutely crucial and something CESA is committed to, especially among healthcare practitioners.



### NEXT STEP - DIAGNOSIS (FOR CLINICIANS)

If a patient experiences these symptoms and you to consider Cauda Equina Syndrome a possibility they ideally require definitive investigation(s) and management to diagnose or rule out the condition within 24 to 48hours of onset of red flag symptoms. This is to optimise the chance for neurological recovery.

### Healthcare Professionals

CESA provides CES red flag awareness training to healthcare practitioners. Permanent CES can often be prevented if the red flags are picked up and acted on promptly. However awareness of the red flags is not always as good as it could be and this is something we can work with healthcare professionals to address.

We strive to aid early diagnosis of the condition and subsequently avoid permanent neurological damage where possible.

### Supporting You

We know that when you have received a diagnosis of CES you may feel scared, bewildered and like the rug has been pulled from under you. However, we can help you to obtain the best possible quality of life by offering you support and signposting you to the organisations that can give practical help, including:

- Support via the CESA helpline - **0333 5 777 113**
- Information about useful products and equipment
- Access to social media support groups and support group meetings

We have first-hand experience of CES and know what help is available from the NHS and how to access it.

To contact CESA call **0333 5 777 113** or email **[info@ihavecaudaequina.com](mailto:info@ihavecaudaequina.com)**