

The back pain you must never ignore: Doctors delayed treating Claire - now she'll never walk properly again

- **Back condition left Claire Thornber, 42, disabled and without a sex life**

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Claire is trying her best to be positive

Claire Thornber is trying her best to be positive. But since a back condition left her disabled, incontinent and without a sex life, it's hardly surprising she sometimes struggles to see the brighter side.

The 42-year-old mother of two girls is scraping by on disability benefits after having to close a successful cleaning business. Her marriage has crumbled. Claire (pictured) doesn't blame her husband, but is furious to be facing a lifetime of pain and loss. What hurts most is that it was all so unnecessary - clear warning signs were missed.

Claire's problem first struck in 2010. She'd been coping with intermittent back pain for years, which came on gradually, with no clear cause. Then one night, turning over in bed, she felt something suddenly 'go'. 'I woke up in agony. I was in so much pain I couldn't breathe.

'I thought "this is something quite scary". It felt completely abnormal,' says Claire. 'In my buttocks and the tops of my thighs, I could feel pins and needles and a heavy feeling.'

With her husband's help, she managed to get out of bed and drag herself into the bathroom.

She went to see her GP that morning. She'd had an MRI scan only three days before, to investigate her back pain - this showed she had a severe prolapse, a slipped disc pressing on a nerve.

Though he hadn't seen the scan, Claire's GP was convinced she was now suffering from cauda equina syndrome and sent her to A&E with a note saying so.

The cauda equina, literally 'horse's tail', is the bundle of nerves at the base of the spine. They control feeling and movement in the feet, lower legs and 'saddle' area - the bottom, genitals, rectum, and bladder.

Cauda equina syndrome is where these nerves become compressed - due to a slipped disc, a tumour or an injury. The result is a contradictory-sounding combination of pain and numbness.

Surgery is the only treatment. If done early enough, this can prevent the syndrome from becoming permanent. But in the worst cases, patients are unable to walk and rely on a wheelchair.

Many face a lifetime of incontinence and sexual dysfunction. While the condition is thought to affect 'just' a few hundred people in the UK each year, the consequences are devastating.

With her GP's referral, Claire should have been passed to a specialist spinal unit when she got to hospital. But the scan results were never passed on; instead she was discharged with a diagnosis of 'spinal stenosis', a narrowing of the spinal canal.

She says: 'I argued with the junior doctor. I said: "I can't feel my bowels or my coccyx. There's something desperately wrong."'

By now, the clock was ticking.

Cauda equina syndrome is where nerves at base of spine become compressed

As John Reynard, a urology specialist at Stoke Mandeville Hospital, explains, the chances of a complete recovery are highest if the patient has surgery within 24 hours. 'If a nerve is being pressed on, its blood supply is being impaired and it will eventually die. The sooner you decompress that, the sooner you ensure it remains viable.'

In the evening, Claire went back to the hospital and was admitted. Cauda equina syndrome was diagnosed, and she was rushed to a larger hospital.

But there were no orthopaedic surgeons free when she arrived, and there was disagreement about the urgency of her case.

Claire was scheduled for an operation first thing the next day, but was shunted down the list. It was lunchtime before she went into surgery, at least 36 hours after the pain first hit.

'The surgery was successful in that I'm not completely paralysed,' says Claire. But because she was sent home without a catheter, she suffered a bladder and uterus prolapse.

Four years on, Claire has been left with partial paralysis of the legs. The pain is always there. She is doubly incontinent and unable to work.

85 per cent

Proportion of back pain patients who have no clear cause of their condition

But the worst thing, she says, is the loss of sexual function, which ruined her marriage. She and her husband have now divorced.

The NHS trust that treated Claire has admitted liability for failing to pass on her scan and is negotiating compensation.

But she wants to make sure others don't suffer in the same way, and has set up the Cauda Equina Syndrome Association to campaign for more awareness of the symptoms and better care.

Eddie Jones, head of medical negligence at JMW, the Manchester firm representing Claire, says: 'There seems to be a significant lack of education across different specialities. I think we've had physiotherapists, GPs, paramedics, junior doctors in A&E, orthopaedic surgeons, even neurosurgeons missing the signs.'

This has cost the NHS dearly. The NHS Litigation Authority has paid out £377 million since 1995 for 159 cases involving cauda equina syndrome. A further 180 cases are still being brought.

The Society of British Neurological Surgeons denies there's a widespread lack of understanding.

Spokesman Rodney Laing, a consultant neurosurgeon at Addenbrooke's Hospital, Cambridge, says: 'It's always helpful to repeat messages, especially to non-specialists, but I don't think there is a mass of ignorance about this.'

He points instead to the early symptoms being difficult to differentiate from the acute back pain that brings thousands of people to A&E each year.

'The problem is that many patients present in the phase before they have the complete syndrome.' Mr Laing adds that sending all the patients with back pain and urinary changes for MRI scans would consume huge amounts of NHS resources.

Claire Thornber is not convinced, and John Reynard agrees. 'I've been involved with 100 cases now and I get the impression that some doctors don't recognise the subtle signs that indicate nerve compression,' he says.

It's not just the physical effects that are so devastating. Callers to Claire's helpline say the NHS has been slow to recognise the psychological shock. 'Men find it very difficult to deal with the fact it makes them impotent. I spoke to one man of 29 . . .' she trails off.

'It's a massive, life-changing thing. Some people never get over it.'

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