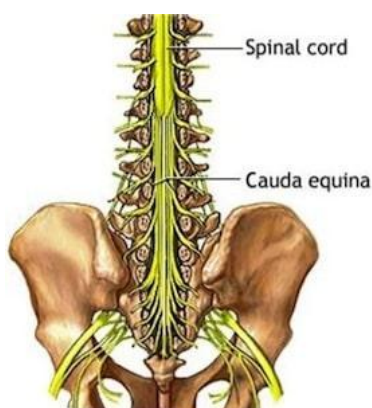


What is functional cauda equina syndrome?

The cauda equina is a bundle of nerve roots found at the bottom of our spinal cord. These nerves are important for the function of our bladder and bowels. They also carry signals from the brain to and from our legs. Cauda equina means 'horse's tail' because that's what it looks like.

Doctors worry about cauda equina syndrome when someone has severe back pain along with bladder symptoms, bowel symptoms and difficulties with strength or sensation in the legs or bottom. They worry that the person may have a slipped disc or something else squashing the cauda equina, so usually an urgent MRI scan is done to find out what is happening.



People with cauda equina syndrome caused by squashing of cauda equina nerves usually need urgent surgery to relieve the pressure on the cauda equina to reduce the chance of nerve damage.

In '*functional cauda equina syndrome*', all the same symptoms are present, but the scan is normal or 'negative'. There is no nerve damage. Around two-thirds of people with cauda equina symptoms are in this category. Recent research suggests that acute pain triggers changes in brain processing which disrupts the way that signals go to the bladder, bowel and legs. We can't see this on a scan because it's to do with the way the nervous system is working. It's a problem with the software of the nervous system rather than the hardware.

This fact sheet is designed to help share what we know about functional cauda equina syndrome and to give you some ideas to help make sense of what is going on.

What sort of problems do people with functional cauda equina syndrome have?

Severe low back pain

Pain shooting down one or both legs

Difficulty passing urine or incontinence

Constipation or other bowel symptoms

Numbness around the bottom or genitals

Weakness or numbness of the legs



FACTSHEET

Case study of someone with functional cauda equina syndrome

Karen is a 44-year-old lady who has had flare-ups of back pain on and off for several years. She bent down to pick up her children's toys and felt a 'snap' in her back, then very severe pain. The pain got worse and worse, and she felt it was hard to breathe. All she could think about was how she was going to be paralysed, and the pain would never go away. She felt a bit "spaced out", she remembers crying for help, and then an ambulance came after what felt like a really long time.

When she got to the hospital, they asked her to move her arms and legs, and then she realised she couldn't move her right leg. It felt like it didn't belong to her. When the doctors were touching it, she couldn't feel her leg. The pain in her back was still really bad. Karen got some intravenous medication, which took the edge off a bit but made her feel woozy. When the doctors checked her back passage, the sensation there felt funny too. Karen didn't feel she could get to the toilet, so the nurses put a bedpan under her, but she couldn't pee. She had to have a catheter put in to be able to pass urine. No one seemed to know what was wrong, but they looked worried, and she was told she would need an urgent scan and may need emergency surgery that night.

The scan was done, and she wasn't allowed to eat or drink for a few hours. Eventually, a doctor came and told Karen her scan was normal. She asked what was wrong and why her leg wasn't working? Why was her back so sore? And why couldn't she pee? The doctors didn't know. Karen was worried; she knew how much pain she was in and knew something must be wrong. The next day her symptoms had improved a little, but she was very worried about what had happened.

How common is functional cauda equina syndrome?

Functional cauda equina syndrome is actually more common than compressive cauda equina syndrome, where the nerves are squashed in the lower back.

*About **two thirds** of patients who come to hospital with cauda equina symptoms have functional cauda equina syndrome*

Until recently, doctors have often just reassured people without cauda equina compression that there is "nothing seriously wrong" or used labels like "acute back pain" to explain their symptoms. Increasingly, doctors are recognising that it is more helpful to think about the

different factors which influence functional cauda equina syndrome to make sure that patients get the right kind of treatment.

How is functional cauda equina syndrome diagnosed?

Functional cauda equina syndrome is recognised when someone has a typical combination of pain, bladder and/or bowel and/or sexual symptoms. There is often some numbness or weakness of the legs. The scan is either normal for age or shows some changes that don't explain the bladder/bowel or sexual symptoms, or leg weakness. If there is leg weakness there are clinical features typical of a functional disorder.

Will functional cauda equina syndrome get better?

Often the symptoms improve spontaneously or with painkillers. Sometimes, people with functional cauda equina syndrome may be left with persistent symptoms, or they may have recurrent episodes of bladder, bowel or sexual dysfunction and weakness along with back pain.



It is really important to know that because there is no damage to the nervous system in functional cauda equina syndrome, there is always the potential to get better. This is true even if you have had symptoms for a long time.

What causes functional cauda equina syndrome?

Functional cauda equina syndrome can happen for several different reasons. It is not possible to identify the exact cause in every individual.

Pain

Functional cauda equina syndrome usually starts with severe back pain or 'sciatica' (shooting pain down the legs). This can come 'out of nowhere', when bending over or twisting your back or after an injury. In some cases, an MRI scan might show the cause of the pain. For instance, there might be a bulging disc, irritating one of the nerves in the back (different to the cauda equina nerves). In other cases, the cause of the pain might not be visible on the scan. Even minor muscle or soft tissue problems in the back can trigger muscle spasm, which is extremely painful (but not visible on scans). For some people, the pain caused by nerve root irritation or muscle spasm is so severe that they may find it difficult to breathe, feel tingling in their fingertips or around their mouth or feel zoned out (the medical word for this is 'dissociation'). Some people may even feel so horrible that they worry they are going to die. These are symptoms of a panic attack triggered by the pain.

Medications

Many people have chronic back pain before they develop functional cauda equina syndrome. Medications used to treat pain like opiates (such as tramadol, cocodamol or dihydrocodeine), gabapentinoids (such as pregabalin or gabapentin) or benzodiazepines (such as diazepam) can interfere with bladder, bowel and sexual function. Many people will feel their back or leg pain getting worse over a few days and will increase their medications as the pain increases.

Pre-existing bladder problems

Around one-third of adult women suffer from some degree of bladder incontinence, and men and women with chronic back pain are more likely to have bladder problems.

When we add acute, severe pain to an already vulnerable bladder and bowel, they can stop working or work too much, causing inability to pass urine or incontinence. We think that these factors affect the bladder, as well as triggering changes in the way that bladder problems are processed in the brain. This affects the normal functioning of the cauda equina (even though there is no damage to the cauda equina itself). Fear or panic caused by pain can also play an important role because being able to pass urine and open our bowels is usually dependent on being able to relax our sphincters. Anxiety can worsen pain, setting up a vicious circle. The physical effects of panic on the body can also make weakness, bladder symptoms and bowel symptoms worse. Changes in the brain's attention system caused by pain, bladder and bowel problems can interfere with normal movement in the legs.

These changes in brain processing can continue even after the original cause of the pain has improved.

Functional Leg Weakness

Many people with functional cauda equina syndrome have leg weakness. This may be related to pain, a trapped nerve or could be due to a functional leg weakness. Functional leg weakness is due to the nervous system not functioning properly. It is

not caused by damage or disease of the nervous system. Patients with functional limb weakness experience symptoms which can be disabling and frightening, such as problems walking or a 'heaviness' down one side, dropping things or a feeling that a limb just doesn't feel normal or 'part of them'. This will be checked for by your doctor and is diagnosed with a positive bedside test, such as Hoover's sign of functional leg weakness. If you have this, your doctor may give you more information about it separately from this factsheet.

This diagram shows how in functional cauda equina syndrome, severe pain can trigger symptoms and set up a "vicious cycle".

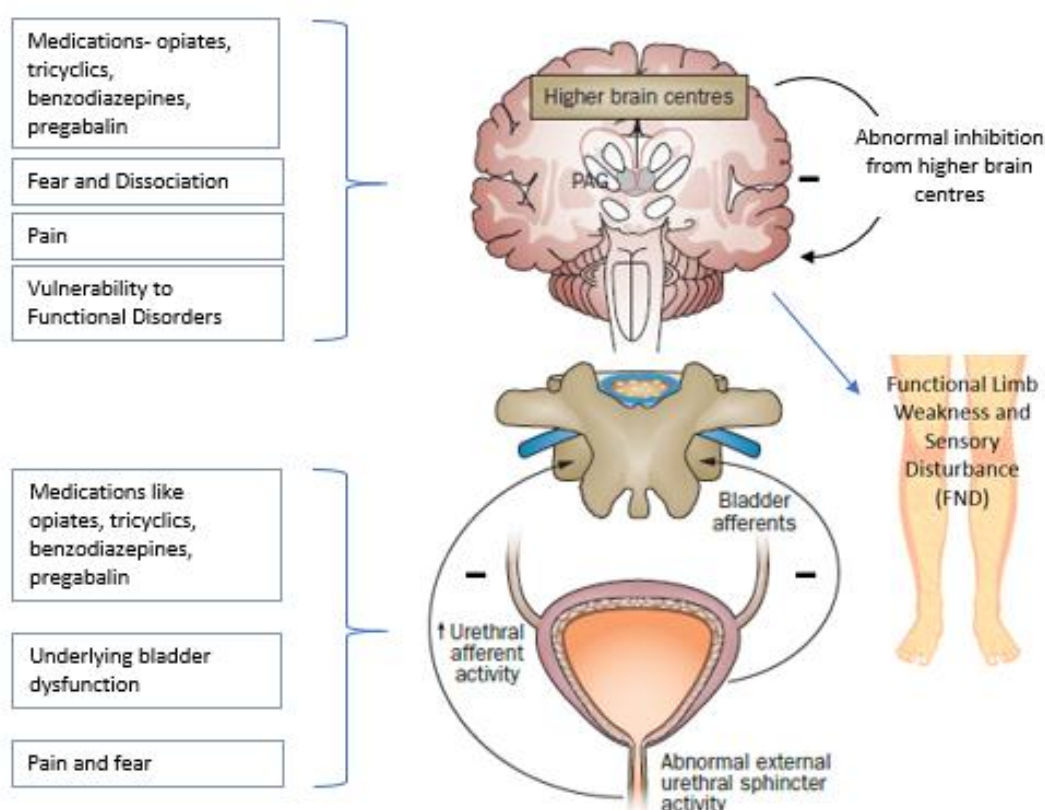


Figure adapted with permission from Osman et al Nature Review Urology 2013

FACTSHEET

MRI Scans and Cauda Equina Syndrome

Everyone with cauda equina symptoms needs an MRI scan to make sure they don't have compressive cauda equina syndrome. Some people with functional cauda equina syndrome do have minor changes on the MRI of their spine. These can sometimes be a cause for pain and a trigger for the symptoms. In other people, these might not be causing any symptoms at all. Either way, these changes don't mean there is a severe disease of the spine.

Changes seen on a spinal MRI may *trigger* cauda equina symptoms, but the symptoms actually come from **changes in the bladder-brain feedback loop and brain processing**. You can't see these on an MRI scan because it only shows the *structure* of the body and not its *function*, the way it's working.

When a problem relates to a change in the *function* of the nervous system, this means the symptoms can improve even if the scan changes remain. We know that rehabilitative approaches to treatment can reverse these unhelpful changes in brain processing.

MRI scans use a magnetic field to take pictures of the body. MRI scans can rule out compressive cauda equina syndrome. They can also sometimes identify a cause of the pain, which may have triggered functional cauda equina syndrome. In other cases of functional cauda equina syndrome, the scan can be completely normal, and the pain is caused by muscle spasm.



Changes in the spine on MRI scanning are very common in healthy people

Studies in 3000 people with NO back symptoms have shown that minor changes in the spine on MRI scanning are really common, affecting >30% of people over 20 and >60% of people over 40.

[Brinjikji et al. American Journal of Neuroradiology. 2015](#)

In a typical person in their 40s WITHOUT BACK PAIN, out of every 100 MRI scans

- 68%** Show "degenerative changes" in the bones and joints.
- 50%** Show minor disc bulges which don't touch a nerve.
- 22%** Show disc bulges which may irritate a nerve but don't cause serious damage.

APPROACHES TO RECOVERY

We've based this part of the factsheet on what has worked in patients we've seen and on the general approaches that enable the best outcome in a variety of neurological disorders.

Does medication help?

When functional cauda equina syndrome first starts, most people need painkillers. Pain medication will try to help the acute pain (pain that lasts for hours to days), and having adequate pain relief may help your other symptoms improve.

Your doctor will be able to advise you on what type of pain medication is best for you, as this may depend on the type of pain you have as well as your other health conditions. If you are not already taking it, it is often best to avoid opioid medications (like codeine and morphine) as these can aggravate constipation and bladder symptoms.



Chronic pain after a few weeks is caused by an increase in the volume knob in pain pathways – not damage to the nerve, muscle or bone.

After the first few weeks, pain medication is often less helpful.

Chronic pain (pain that lasts months or more)

is very different from acute pain. It's called

Chronic Nociceptive Pain and usually arises

from changes in pain processing in the brain,

rather than relating

Research shows that after 12 weeks, opioids like cocodamol or morphine are no more effective than placebo at treating persistent chronic pain

directly to tissue damage. A lot of people with functional cauda

equina syndrome will have chronic back pain and may be on medications for it.

Chronic pain often does not respond to medication, especially opioids, but can be treated using other ways such as pain management strategies and rehabilitation.

Managing bladder and bowel symptoms

Many people with functional cauda equina symptoms will have a catheter inserted to allow them to pass urine when their symptoms first start.

But it is important to re-train the bladder as soon as possible, so the catheter will only be a short-term measure. Sometimes, a type of catheter called a "flip-flow", which helps the person become aware of their bladder, is the first step before the catheter is removed. Sometimes laxatives are helpful to make it easy to open your bowels. Usually, these can be stopped as time goes on. Nurses or sometimes continence advisers will be able to help with this.

Taking a rehabilitation approach to recovery

1. **Keep moving**

Understandably, some people with functional cauda equina syndrome are frightened to move about or walk in case they make their symptoms worse. At the beginning, it may be impossible to walk until your pain is under control, but it's important to get up and about as soon as you can.

It is better to avoid using sticks and walking aids wherever possible, as these tend to activate abnormal patterns of movement in the brain.

It is vital to get moving as soon as possible to “re-train” your brain in normal movement patterns

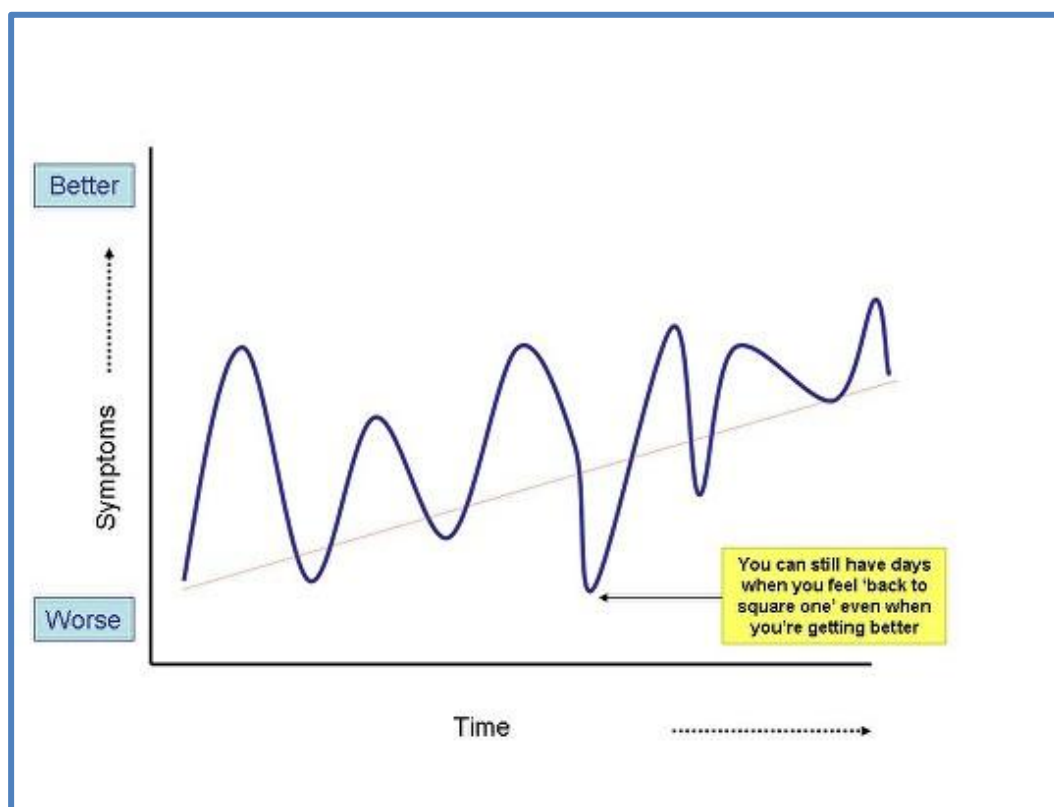
Gradually build up your levels of activity

People living with persistent physical symptoms sometimes get into a “boom and bust” pattern. This is where they push themselves so hard on good days that they then feel much worse for several days afterwards.

It is better to try to even out your activity by doing a bit less on good days but a bit more on bad days. Once you have achieved this, you can gradually start to build up your levels of activity.

Most people have good and bad days, and you may even have days when you feel you are “back to square one”. Although this can be demoralising, it doesn't mean you can't continue to recover.

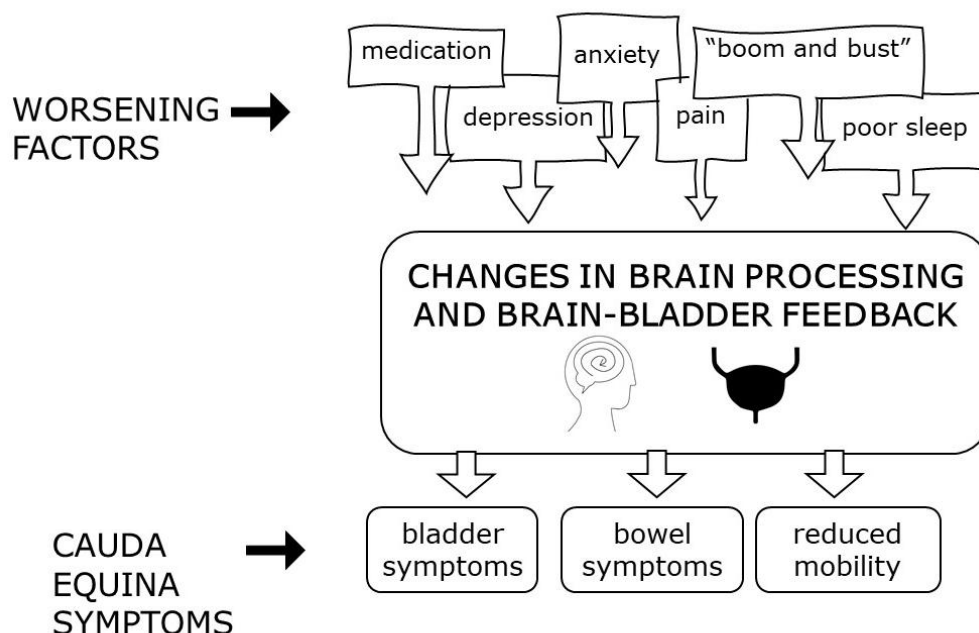
Although too much activity can make symptoms worse, this doesn't mean you are causing damage as long as you take it slowly



2. Manage any worsening factors

It is important to identify any factors that could be making your symptoms worse, so that you can try to change them where possible.

- **Are you on any medication that could worsen your symptoms?** Some painkillers (especially opioids like codeine and morphine) and other medications can cause constipation and or make it harder to pee. If so, ask your GP or consultant to review whether these could be adjusted. Many people will find their chronic pain is the same when they are taking their medications as it was before they started them, but they also have medication side effects. A gradual approach to reducing medications can be hard to achieve and may lead to pain flaring for days or weeks before it returns to where it was, but may have long-term benefits.
- **Is your sleep pattern good?** If not, try to follow “sleep hygiene” advice to improve this. Gentle movement can also improve our sleep and general well-being.
- **Are you living with chronic pain?** If so, you might benefit from learning pain management strategies. You could discuss pain management treatment or referral with your doctor.
- **Have you stopped enjoying anything?** If living with pain and other symptoms means that you no longer enjoy anything or you feel constantly on edge, then you may have depression or anxiety. If so, ask your doctor if you might benefit from treatment for these.



FACTSHEET

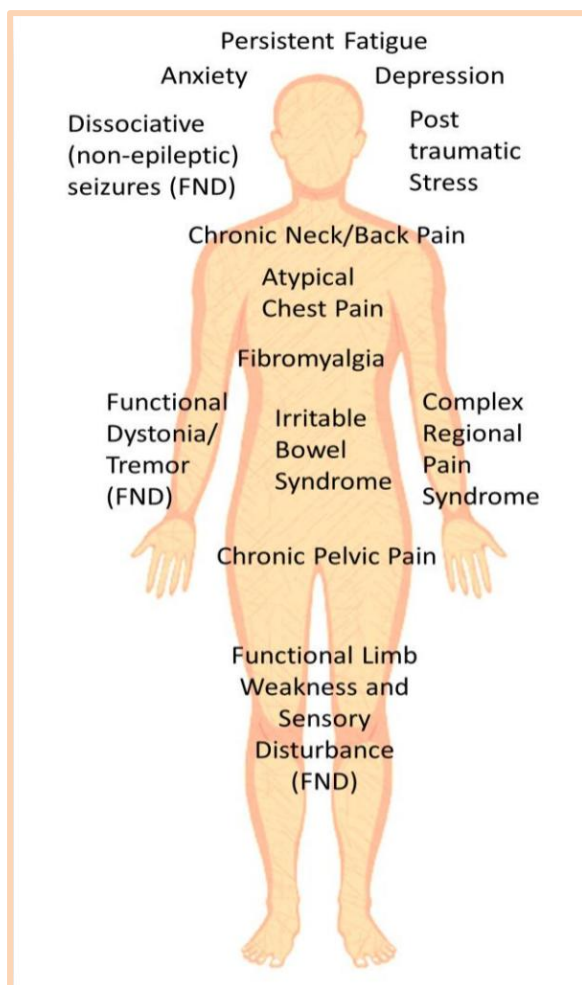
3. Learn to change your own 'automatic thoughts' about your condition

Try to start noticing the automatic thoughts that spring to mind when you experience pain. Challenging these thoughts can help your brain start to work in a more normal way.

For example:

| OLD THOUGHT | | NEW THOUGHT |
|---|---|---|
| This pain is severe, there must be some damage to my back. | ➡ | Muscle spasm can cause severe pain, but it doesn't mean there's any damage. |
| If I move too much when I'm in pain, I could do serious damage to my nerves and end up paralysed. | ➡ | Moving will help to train my brain to work normally again and can't do any damage to my nerves. |
| I will never get rid of this back pain, my life will always be limited by the pain. | ➡ | It may not be easy, but the pain can improve. If I can do something I enjoy, the pain may be more manageable. |
| I won't be able to play with my children because of these symptoms. | ➡ | I might have to do things differently for a while, but I can gradually recover. |

Looking at the bigger picture



In some people, functional cauda equina syndrome is part of a bigger picture of ill health. Studies show that people with this problem are more likely to experience one or more functional disorders. Functional Disorders are a range of common medical conditions which, like most people with functional cauda equina, are the result of abnormal nervous system functioning.

Functional cauda equina syndrome is more common in people with chronic pain conditions like fibromyalgia and irritable bowel syndrome. Some people with functional cauda equina syndrome might also have anxiety or depression. Sometimes depression and anxiety are a consequence of the stress of the condition itself.

Many people who have functional cauda equina syndrome have NONE of these other health problems, so please don't be put off if this section doesn't apply to you. But if it does, it may be worth spending time with a health professional who understands these disorders to see how these conditions may relate to each other.

Physiotherapy

Many people with functional cauda equina symptoms will need physiotherapy to help improve their symptoms. Physiotherapists can provide advice about movement during back pain flare-ups. If you have functional leg weakness, a physiotherapist can teach you techniques that help to re-activate normal movement patterns and can also give you a graded activity programme to build up your activities.

Continence advice

Bladder and bowel symptoms often improve quite quickly, but if this is not the case, don't be discouraged. Most GPs will have access to continence advisers, who can help you to manage any persistent bladder or bowel symptoms. For instance, many

FACTSHEET

women have stress incontinence, which can be cured in up to 80% of people with pelvic floor exercises.

Psychological therapy

Some people might benefit from a psychological therapy called Cognitive Behavioural Therapy, which is often used to support people with chronic illnesses. It involves learning more about your symptoms and what factors may contribute to them, and learning specific techniques to manage them (such as distraction and relaxation).

Further information



FND Guide - www.neurosymbols.org

This website and app explain more about functional disorders and functional neurological disorder (FND) in particular, if that is relevant to you. It hosts this sheet.

| | |
|--|---|
| Chronic pain in general | www.tamethebeast.org www.flippinpain.co.uk |
| Useful information about incontinence in women | https://www.nhsinform.scot/healthy-living/womens-health/middle-years-around-25-to-50-years/pelvic-health/urinary-incontinence-in-women |

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Scientific Article: Hoeritzauer I, Stanton B, Carson A, *et al* 'Scan-negative' cauda equina syndrome: what to do when there is no neurosurgical cause. *Practical Neurology* 2022;**22**:6-13. <https://doi.org/10.1136/practneurol-2020-002830>