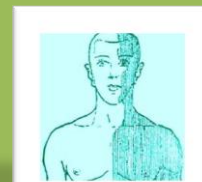


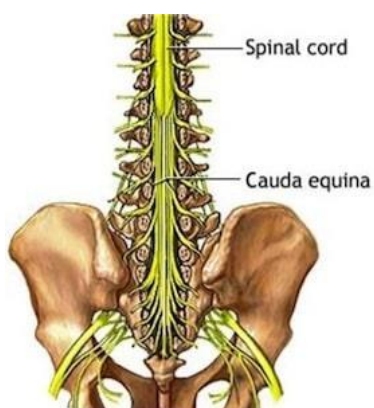
'Scan-Negative' Cauda Equina Syndrome



What is 'scan-negative' 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 '*scan positive*' cauda equina syndrome usually need urgent surgery to relieve the pressure on the cauda equina to reduce the chance of nerve damage.

In '*scan-negative*' 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 its 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.

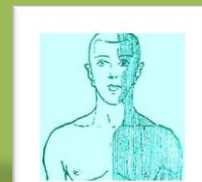
This factsheet is designed to help share what we know about scan negative cauda equina syndrome and to give you some ideas to help make sense of what is going on.

What sort of problems do people with 'scan-negative' 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



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Case study

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 on 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 them. 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 bed pan 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 and drink for a few hours. Eventually, a doctor came and told Karen her scan was normal. She asked what was wrong and why wasn't her leg 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 'scan-negative' cauda equina syndrome?

'Scan-negative' cauda equina syndrome is actually more common than compressive cauda equina syndrome.

*About **two thirds** of patients who come to hospital with cauda equina symptoms have 'scan-negative' cauda equina syndrome*

'Scan-Negative' Cauda Equina Syndrome



Until recently doctors have often just reassured people without cauda equina compression that there is “nothing serious wrong or used labels like “acute back pain” to explain their symptoms. Increasingly, doctors are recognising that is more helpful to think about the different factors which influence ‘scan-negative’ cauda equina syndrome in order to make sure that patients get the right kind of treatment.

Will ‘scan negative’ cauda equina syndrome get better?

Often the symptoms improve spontaneously or with painkillers. Sometimes, people with ‘scan-negative’ 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.

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It is really important to know that because there is no damage to the nervous system in ‘scan-negative’ 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 'scan-negative' cauda equina syndrome?

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

Pain

'Scan-negative' 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, causing irritation to 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 they may find it difficult to breathe, feel tingling in their finger-tips 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 'scan-negative' 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 bowels they can stop working or work too much, causing inability to pass urine or incontinence. We think that these factors have an effect on the bladder as well as triggering changes in brain processing which interfere with the brain-bladder feedback loop. 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 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.

'Scan-Negative' Cauda Equina Syndrome



Functional Leg Weakness

Many people with scan negative cauda equina syndrome have leg weakness. This may be related to pain 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 weakness experience symptoms of limb weakness 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 to this factsheet.

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

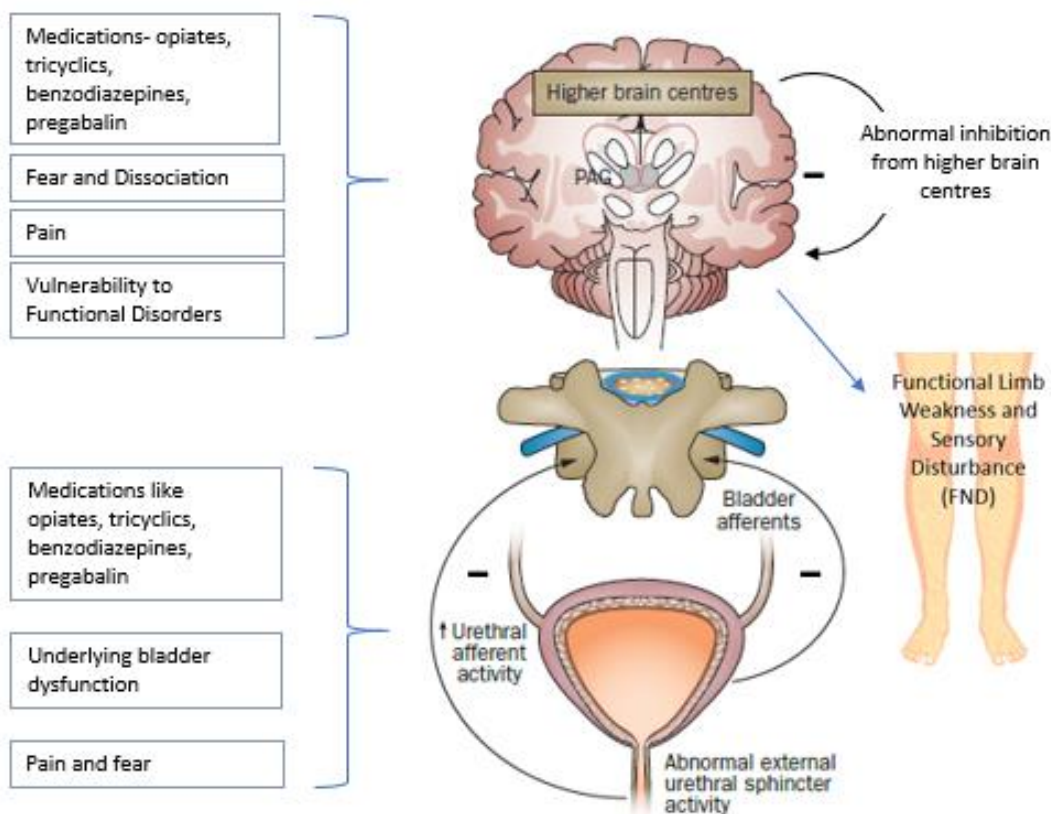


Figure adapted with permission from Osman et al Nature Review Urology 2013

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'Scan-Negative' Cauda Equina Syndrome



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How is the diagnosis made?

Everyone with cauda equina symptoms needs an MRI scan to make sure they don't have compressive cauda equina syndrome. Some people with 'scan-negative' 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. Whilst changes like this may *trigger* cauda equina symptoms, the symptoms actually come from **changes in the bladder-brain feedback loop and brain processing**. 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 sometime identify the cause of the pain which may have triggered 'scan-negative' cauda equina syndrome. In other cases of 'scan-negative' 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

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 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 causes serious damage



APPROACHES TO RECOVERY

We've based this part of the sheet 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 'scan-negative' cauda equina syndrome first starts, most people need pain-killers. 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 to 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.

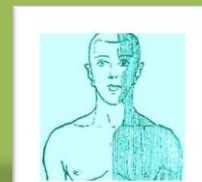
In the longer term, pain medication is often less helpful. Chronic pain (pain that lasts months or more) is very different from acute pain. It usually arises from changes in pain processing in the brain, rather than relating directly to tissue damage. A lot of people with 'scan-negative' cauda equina 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.

Research shows that after 12 weeks, opioids are no more effective than a placebo in treating persistent pain. Long-term opioid use can reduce quality of life and actually cause more pain

Managing bladder and bowel symptoms

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

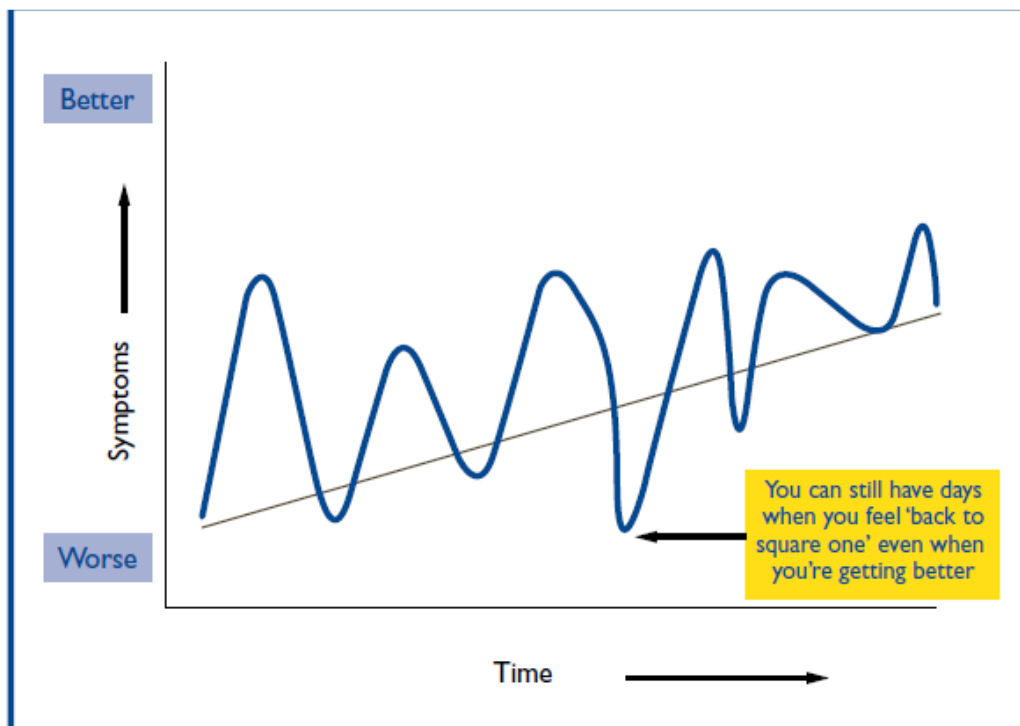
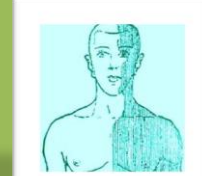
Gradually build up your levels of activity

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

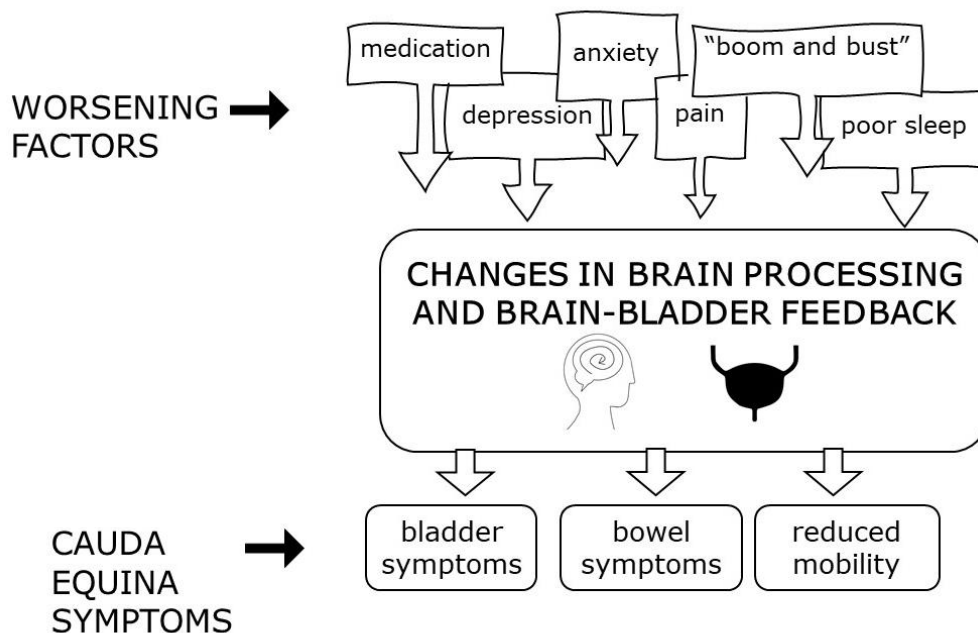
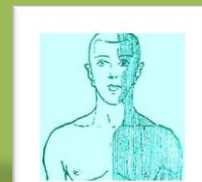


2. *Manage any worsening factors*

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 back 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. Exercise 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 things which you previously enjoyed now seem difficult 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

'Scan-Negative' Cauda Equina Syndrome



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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:

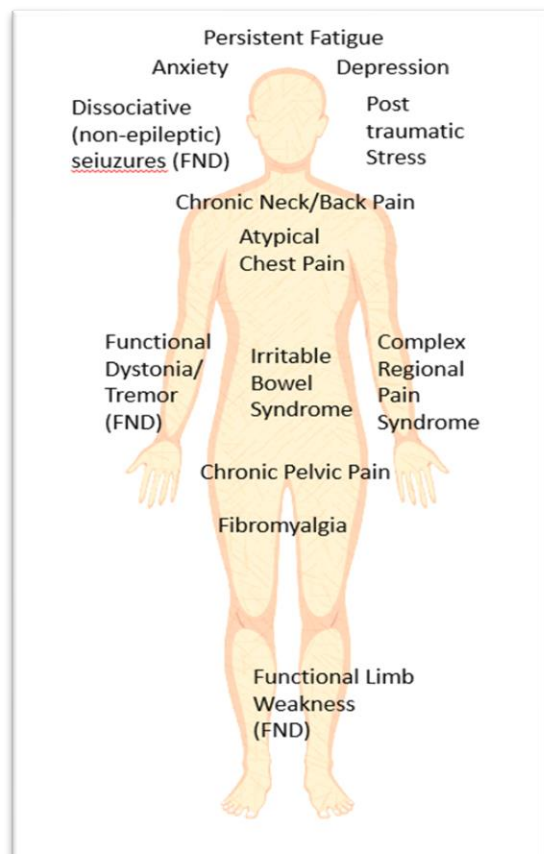
OLD THOUGHT		NEW THOUGHT
This pain is really severe, there must be some damage to my back	➔	Muscle spasm can cause severe pain, but it doesn't mean there's any damage
If I move too much when I'm in pain, I could do serious damage to my nerves and end up paralysed	➔	Moving will help to train my brain 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

'Scan-Negative' Cauda Equina Syndrome



Looking at the bigger picture

In some people, 'scan-negative' 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'.

These are common medical conditions which, like most people with scan-negative cauda equina syndrome, are the result of abnormal nervous system functioning of the nervous system.

'Scan-negative' cauda equina syndrome is more common in people with chronic pain conditions like fibromyalgia. It also seems to be commoner in people with irritable bowel syndrome.

Some people with 'scan-negative' cauda equina syndrome might also have anxiety or depression. Sometimes depression and anxiety is a consequence of the stress of the condition itself.

Many people who have 'scan-negative' 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 'scan-negative' 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 exercise programme to build up your activities.

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'Scan-Negative' Cauda Equina Syndrome



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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 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



www.neurosymptoms.org

This website explains more about functional disorders and functional neurological disorder (FND) in particular, if that is relevant to you.

BackCare	www.backcare.org.uk
British Pain Society	www.britishpainsociety.org
American Academy of Pain Medicine	www.painmed.org
Pain Concern	www.painconcern.org.uk
Pelvic Pain Support Network	www.pelvicpain.org.uk
Fibromyalgia Association UK	www.fmauk.org

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Scientific Article: Hoeritzauer et al "Scan-negative" cauda equina syndrome: A prospective cohort study. *Neurology* 2020. DOI: <https://doi.org/10.1212/WNL.0000000000011154>