

## If only I had known these things about sciatica!

Low back pain with sciatica is associated with increased pain and disability compared to low back pain alone. For some the pain will resolve naturally in a few weeks, however for others it can remain for months or become permanent.

This IASP factsheet is one of the first to be written by a person with lived experience of a condition, rather than a clinician.

I have lived with sciatica and accompanying low back pain since the summer of 2008, and fully expect to live with it for the rest of my life. I have both neuropathic pain and neurological deficits, arising from both a compressed nerve root and irritation/inflammation of the nerve root following a prolapsed disc. My nerve root is both tethered to my disc and tethered within itself.

My journey with sciatica has been difficult at times, and I have learnt a great deal along the way. I am aware that my 'damaged' nerve root, and associated inflammation, is the main driver/factor in my sciatic pain experience, but around four years into my pain journey I was helped to discover there are many more casual factors. I have been helped to understand the nature of neuropathic pain, and to understand MY individual sciatic condition. Through this understanding I have become better able to manage my condition and better able to live a good life with pain, without my initial over-reliance on medications, injections and surgery.

I often wonder if my journey with sciatica would have been easier if I had known from the beginning what I know now. I can't turn my own clock back, but perhaps some of my thoughts and reflections in this factsheet could help clinicians to improve their treatment of people with sciatica, and also help people living with sciatica understand and manage their own sciatica better than they do.

## Sciatica means different things to different people

My journey with sciatica started with a manual handling incident. In simple terms I herniated my L5/S1 lumbar disc and my S1 nerve root was compressed and inflamed. I was in dreadful pain, unable to walk, sit or stand. After 5 days of hospitalisation I was discharged, bewildered by strong medication and still in dreadful pain. Over the next few weeks, I had to regain the ability to walk, but it took much longer to be able to sit down for even a few minutes. I had back surgery just over a year later, which removed the compression on the nerve. Unfortunately, by then my nerve root was permanently 'damaged', as was my back. Since that fateful manual handling injury, I have been on a long journey of recovery and rehabilitation with many, many ups and downs.

The 'official' diagnosis given to me was 'disabling right sided sciatica', but clinicians didn't really explain to me what that meant. I spent years trying to work it out. I now understand that there is no commonly agreed 'definition', or shared understanding, of the term 'sciatica'. Different clinicians have different views, and the information available to the public on the Internet, or within books or papers, reflects that lack of consensus. There is not even a consensus as to whether sciatica is a symptom of another condition, or a diagnosis in its own right. As a patient desperate for understanding I found it confusing navigating such disparate information. For many years I yearned to have a better understanding of my condition. I yearned for there to be a simple definition of sciatica that all clinicians agreed and subscribed to.

In strict and simple terms sciatica is the name given to pain caused by irritation of one or more of the nerve roots in the lower back. Pain might be felt anywhere around and along the path of the sciatic nerve, even though the actual irritation is at the site of one of the nerve roots in the lower back. Although sciatica may be associated with neurological dysfunction, such as weakness and numbness, the term sciatica only

describes the pain element. Sciatica is a symptom rather than a specific condition, illness or disease, and not a 'diagnosis'.

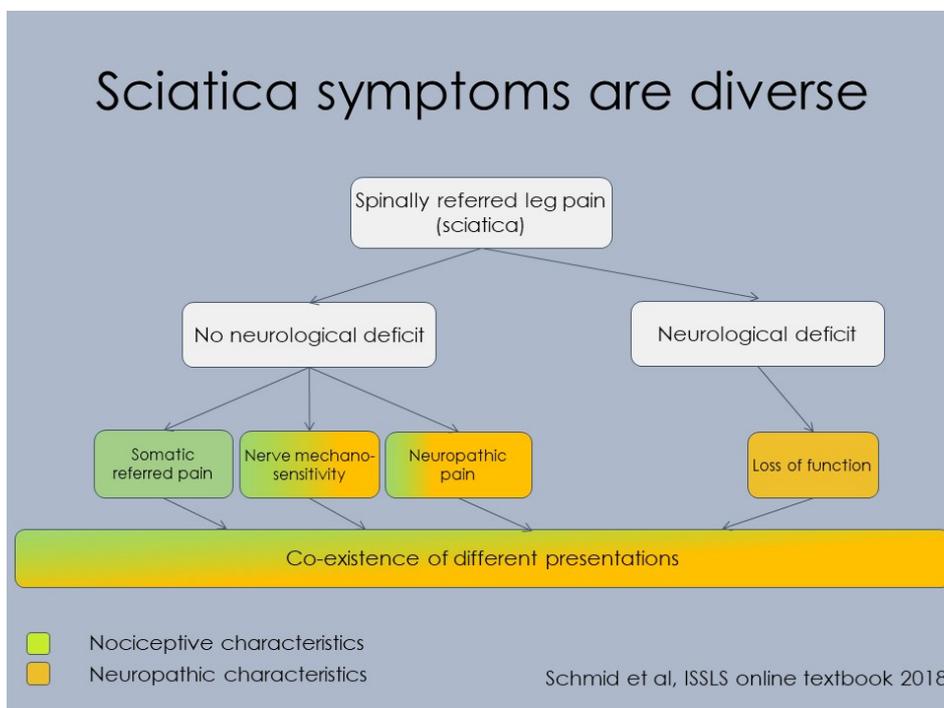
However, it is commonplace for clinicians to refer to sciatica as including both the pain element and any neurological deficits such as numbness, reflex loss and motor weakness, and it is commonplace for clinicians to give a 'diagnosis' of sciatica. Sciatica seems to be used as a 'catch all' term, even sometimes being used for leg pain that does not involve the nerve roots in the back at all. These usages of the term 'sciatica' may not be strictly accurate, but they are very common.

I now happily use the colloquial term 'sciatica' to describe my overall condition, including my sciatic pain, weakness, numbness, and all the weird nerve sensations that I experience that I have learnt to accept as part of my life. I have learnt to ignore all the 'noise' around the use of the term 'sciatica' and I have learnt to accept that 'sciatica' means different things to different people, and that's fine. I wish I had been helped to navigate the often confusing and disparate understanding of the term sciatica at the beginning of my journey. It would have saved me much angst and confusion.

### Sciatica is a spectrum

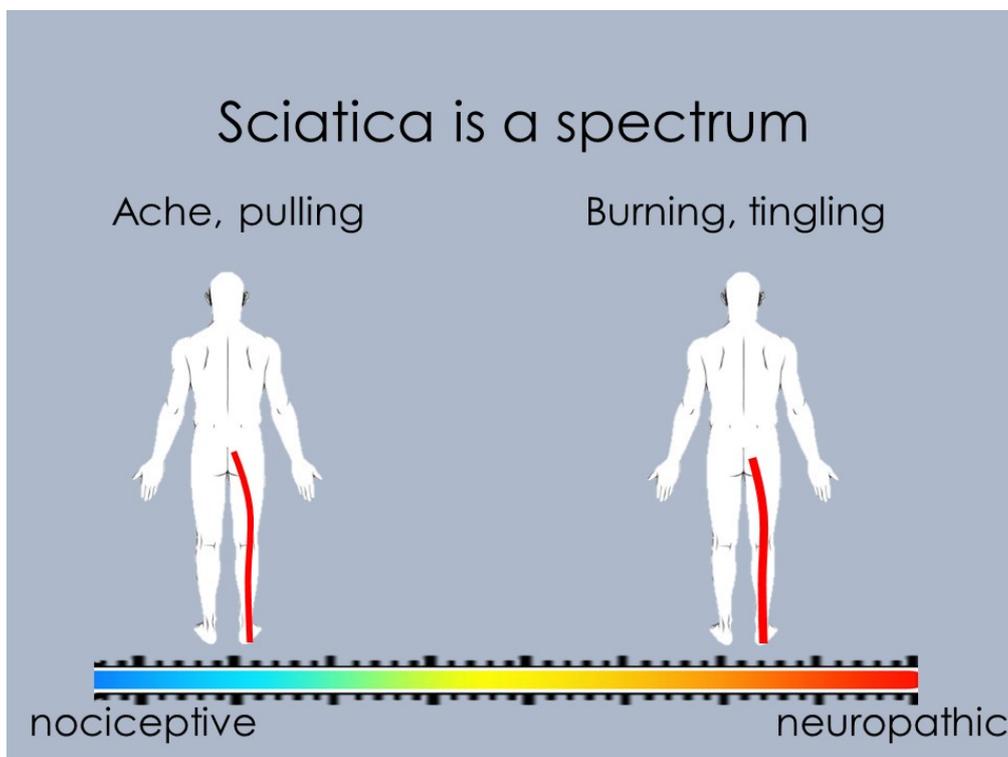
Sciatica is a very common condition, affecting 10% to 40% of the population. I don't intend to go into the physiology of sciatica, or how it is caused, in this factsheet, I will leave clinicians to do that elsewhere. As a person living with sciatica, I am more concerned about the symptoms I experience and how to manage them, rather than the detailed physiology involved.

At the beginning of my journey, I assumed that everyone with sciatica would have the same symptoms and experiences as me, but I now understand that sciatica is a spectrum. This diagram helped me to understand the diverse range of symptoms involved in sciatica.



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Another diagram that I found particularly helpful when learning about my own condition is the one below. It helped me understand that sciatica really is a spectrum and that the different qualities of pain that I was experiencing were normal.



*Re-printed with permission from Annina Schmid, University of Oxford.*

In a strange way this diagram also helped me to accept that my own sciatica was at the more severe end of the spectrum, and that was ok.

Looking back, I would say that right from the start of my journey I needed to have a better understanding of the range of symptoms involved in sciatica, and how my own case fitted into the sciatic spectrum. I needed to understand more about why some of my pain felt totally different to that I had experienced before, and how to manage it. I needed to understand about neuropathic pain.

### **Neuropathic pain is different**

As part of my sciatica I have neuropathic pain, sometimes severe. Neuropathic pain is not like any pain I have experienced before. It is unpredictable and can appear as if out of nowhere. The pain can be constantly present, or it can vary, sometimes wildly! It has a severity and tenacity that leaves my other pain looking like a shrivelled prune! This unpredictability and severity have caused me anxiety and feelings of dread and despair. I have experienced times when I have been fearful of the future. For many years, my fear and despair were fuelled by a lack of understanding of my condition, and in particular neuropathic pain.

My first real understanding of neuropathic pain occurred a couple of years into my journey when I read some other people's stories on the Neuropathy Trust website. I can remember exactly where I was when I read these stories, and the emotions I felt are still palpable, it was that important to me. I found that I could identify with all the weird and wonderful sensations and pain that people were describing, and this provided me with a sense of understanding and relief. The experience of being able to identify with others going through similar experiences was simply life changing for me.

Neuropathic pain is caused by a lesion or disease of one or more nerves in the body (including the nerve roots that cause sciatica). People describe and experience neuropathic pain in different ways. Some of the words I use to describe my neuropathic pain are excruciating, burning, electrical, lightning, sharp, shooting, searing, stabbing, tingling and cramping. I sometimes refer to having 'fairy lights' in my leg, and I sometimes refer to having a 'woollen feeling' in my leg.

Neuropathic pain 'behaves' and 'feels' very different to any other pain I have experienced, and I have found I have had to find different ways to manage this type of pain.

I have found that my sciatic pain is very affected by what I do during the day, and that my pain is usually worse during the evening and night. I experience 'wind-up' of neuropathic pain, which to me means that if I keep physically irritating my sciatic nerve through, for example, lifting, carrying, sitting and walking then it becomes more and more irritable, and increasingly painful, as the day goes on.

Essentially, I think of my nerve root as being temperamental and easily 'wound-up' by a variety of triggers, sometimes becoming explosive. I know that if I continue to irritate the nerve then I can expect to experience 'lightning bolts' of severe pain, most likely waking me up at night, and/or moderately severe pain mainly in the evening which often feels like a cramping pain. These bad episodes of pain can last around 30 minutes, which at the time feels like a lifetime!

I visualise this neuropathic pain wind-up process in a similar way to a parent being wound up by a child. The more the child aggravates their parent throughout the day the more temperamental and explosive they may become.

Fortunately, if I am careful to minimise aggravating my condition during the day or evening, then my nerve root and consequential pain usually settles back down over-night and I start a new day with similar levels of pain to those I started the day before with.

Understanding more about the nature of neuropathic pain, and how to manage it, has been key to me being able to positively move forward with my life with pain, and has been key to my mental well-being. I wish that neuropathic pain and 'wind-up' pain had been better explained to me from the start of my journey. I needed that understanding, and with it I am sure my journey with sciatica would have been much smoother and less traumatic.

### **Persistent sciatic pain has wider causal factors**

For the first four years following my injury I was treated within a narrow view of pain. I was given epidural injections, powerful pain medications, back surgery and physiotherapy. Looking back, I don't think I was in control of my pain situation. I was struggling day to day, not knowing how to improve my situation. Medications weren't helping sufficiently, and nor were the injections or surgery. Living with pain was proving very difficult, and I didn't know where to turn.

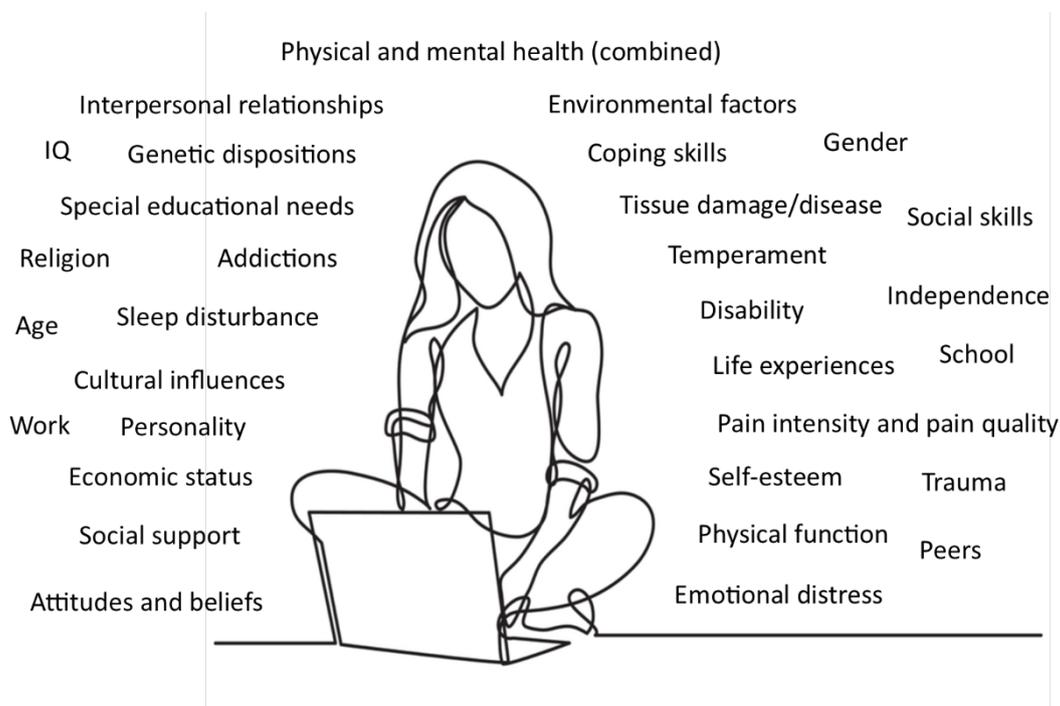
I assumed that someone somewhere would be able to 'fix' my sciatica and that I would no longer be in pain. I just had to find them. I wasn't helped to understand that sciatica can be a lifelong condition, and that I could be in pain every day for the rest of my life. I needed to be told this right from the beginning. I needed to understand and accept this so that I could move on. I needed to understand that a 'fix' is not always possible, but that there are treatment options that can help. I needed to know that with support I could go beyond simply taking medications and start to understand and self-manage my pain.

Around four years into my pain journey I was treated by a physiotherapist who took a different approach to my care. He helped me understand that there are much wider causal factors to my pain experience than just what was physically happening with my nerve root and my lower back. He helped me understand the nature of neuropathic pain, and the complex nature of the experience of pain in general. He helped me learn to self-manage my pain.

Sciatic pain, like any pain, is complex. As well as the physiological factors involved (in my case my previously compressed nerve root and it's tethering, changes in my back from surgery and probably some associated CNS changes) there are many other causal factors involved in the experience of pain.

I have no doubt that we all feel pain differently. In the same way I experience happiness, or sadness, or fear differently to you, then I am sure I feel pain differently too. If we both put our fingers on the same hot stove then we would likely experience different levels and sensations of pain, according to our own unique physiology, genetics, psychology and life experiences. My experience of pain is affected by who I am, how I feel and what I do, as is yours. Pain is an individual experience, unique to the individual person and their circumstances at the time.

In the diagram below I have tried to depict some of the factors that might impact on my presenting health and persistent sciatic pain. Historically these areas might have been split into three separate circles (Bio, Psycho and Social), but I choose to depict them simply as a range of factors that affect me as a unique human being. I defy anyone to separate out the complexity of who I am, and the complexity of my persistent pain condition, into the three distinct areas of Biological, Psychological and Social. Where would the lines get drawn? Everything about me and the world I live within dynamically combines, interacts, and overlaps. There are no distinct boundaries.



*Who I am, what I feel, and what I do, affects my experience of pain, by Christine Price*

It is impossible to tell from this diagram how each of these factors affect me as an individual person. It would only be by listening to my 'story' that you could start to understand. I was lucky to find a physiotherapist who took the time to 'listen to my story', and who enabled and empowered me through knowledge and understanding to better manage my sciatica. He helped me to identify a range of day-to-day factors that were positively or negatively affecting my sciatic pain. I learnt to understand that negative

factors such as stress, fear, anxiety, lack of sleep, cold weather, lifting, sitting on hard surfaces were likely to increase my overall pain, whilst positive factors, for example when I am with friends, when I am gently walking or when I am immersed in a book were likely to decrease my overall pain. I could not eliminate my pain, or change my genetic dispositions, personality, temperament, or the physical changes that had taken place in my body, but with his help I learnt to change my pain experience by minimising as many negative factors as I could and maximising the positive ones. Through understanding the range of different factors that were affecting my experience of sciatic pain, I could start to work out how to optimise those factors to live the best life I could with my sciatic pain.

For the first four years of my journey with sciatica my focus had mirrored that of my clinicians. It was firmly placed on my prolapsed disc (described to me as a 'slipped disc') and damaged nerve root. I had needed my clinicians to widen their focus and help me widen mine. I had needed to understand so much more about the wider causal factors in my experience of pain. Once I was given this understanding my world opened, and I was able to start to self-manage my sciatic pain and live a much better life. The door was opened for me to stop taking medications, stop seeking 'fixes' to my pain, and start to live a better life with pain. Understanding that there are wider causal factors to my sciatica pain than just my 'damaged' nerve root quite literally changed my life!

### Final thoughts

Looking back to the beginning of my pain journey I could not imagine that I would ever be saying that I live a good life with pain, but I do.

Being given better information and support right from the start of my journey would not have ended my sciatica journey, but perhaps it could have made the difficult parts a little easier. Perhaps I could have learnt to better self-manage my sciatic pain and live well with pain much earlier. Perhaps I could have taken less medications and relied less on injections and surgery. Perhaps my journey with sciatica could have been so much easier, if I had only known at the start of my sciatic journey everything I know now!

I do not understand why as a patient I was not given better information about sciatica right from the start, such as that described in this factsheet, but I know it would have made a huge difference to me. I hope clinicians reading this will consider providing better and earlier information to their sciatica patients. Or maybe you already do?

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