Transcript

385R- Restless Legs Syndrome with Dr.Julian Spinks

Steven Bruce

Music. Good afternoon.

Thank you for joining me today. I have to say, it seems much longer than just two weeks since our last broadcast, but I'm very much looking forward to getting back into our regular routine now that the summer break well, my summer break, anyway, is over before we start today. I would like to say a special hello to the quite large number of newbies who are with us today. If you're one of them, you are very welcome, of course, and I hope you'll find lots to take away from today's CPD. It really is a very interactive process, so don't hesitate to join in in the conversation, in the chat lines, or particularly to send your questions through to me so that I can put them to today's guest. You don't have to ask a question if you don't want to. Of course, it still counts as learning with others for your CPD record, but it's always that much more lively and engaging when we get lots of participation. So please don't hold back. Now, normally, I try to get my guests into the studio here, where we can do much more in terms of practical demonstrations and so on, but that wasn't possible today, and Dr Julian Spinks is joining me via the virtual link. Dr Spinks is an advisor to RLS, UK, which has been going for just over 12 years, I think, and he's here to tell us more about restless legs syndrome, and in particular, how it might affect our own practices and our own patients. Dr Spinks, Julian, good afternoon. Thank you for giving up your time to be with us today. I thought we'd start off first of all, I mean, you're a GP of what over 30 years experience now, but here you are, your chairman of RLS, UK, restless leg syndrome. UK, What's your connection to Restless Leg Syndrome?

Julian Spinks

Well, although I'm a GP when it comes to RLS, actually, it's because I'm a patient. I first started to have the symptoms in my 20s, I think. But like an awful lot of people, it was probably 1520, years before I found out what was going on. And so that's my big link. And for a long time, I've been involved with the RLs sort of community, helping people, advising people, and then about six years ago, they asked me to become the chair of the RLs UK charity,

Steven Bruce

right? And you're also a board member for the European Federation of neurological associations. I think is that connected to RLS as well?

Julian Spinks

It is because there's a European Association for restless leg syndrome, which is a member of that organization, and ethno which is a lot easier to say, actually lobbies on path for people with neurological conditions across Europe, including the UK. Because although we're not in the EU, we are definitely still in Europe,

Steven Bruce

absolutely. And before we get into the meat of this I was also taken by when I looked at the the charity RLS UK, I see it's also the charity for Ekbom syndrome, which is delusional parasitosis. So perhaps we can talk a bit about that later as well. I don't know if that's right. Well,

Julian Spinks

you've got the wrong bomb syndrome. Unfortunately, the answer is that the other name for restless leg syndrome is Willis Ekbom, and the the first name Willis was Thomas Willis, who, in 1672 first described the symptoms of RLS. And then Ekbom was a Swedish neurologist who coined the term Restless Leg Syndrome, albeit it's right, of course, right 1950s and unfortunately, he also came up with this other sort of parapsychosis condition. But it's one of the problems with having people naming more than one disease.

Steven Bruce

Yeah, indeed. Well, I stand correctly. Thank you for that. But in my defense, that's how it's listed on the charities Commission website, is egg bomb syndrome. So we'll we'll ignore the delusion of parasites, and we'll talk about restless legs.

Julian Spinks

We're looking to change the name so we get the Willis bit in, because a lot of places in Europe are starting to drop the Restless Leg Syndrome tag, because people feel it sounds trivial.

Steven Bruce

Well, yeah. And I guess I think we can all understand that. We can relate to that, can't we? Because, certainly, as a practitioner myself, in the past, I mean, people have talked about restless legs, and I think, oh, you're a bit fidgety. So what? What is it like? What are the actual implications for a patient, for a sufferer?

Julian Spinks

I think first thing to say is what it isn't, which is jiggly legs, the sort of thing people do when they're sitting there, maybe if they're a bit nervous and so on, very definitely not that restless leg syndrome is defined by a series of criteria, actually only four, and the key one is an almost irresistible urge to. Move your legs, which is associated with unpleasant, sometimes painful sensations, which could be throbbing, burning, strange feeling of sort of bubbling in the veins. People talk about having insects under the skin and so on. And that sensation and that need to move builds and builds and builds until you have to move. The second criteria is that when you do move, you get some relief, but only temporary, and it can then come back again. Third thing is that this happens when you're at rest, and that is sort of when you're sitting or lying down or trying to sleep. And finally, it tends to be worse in the evenings and get better in the mornings. Having said all of that, when the disease gets more serious, it can spread from the legs to the arms, sometimes to the trunk. It can happen earlier in the day. And also, you can have an association with periodic, periodic limb movement of sleep, which is a forced dorsiflexion of the foot lasting between half a second and five seconds occurring every 30 to 40 seconds, which can happen all night. And obviously that's very distressing, both the person who has it, and also, if they have a partner, being in a bed with somebody who's jerking continuously all night is not good news.

Steven Bruce

Yeah, you said that happens while they're asleep. Does that mean that it wakes them up from sleep, or do they wake up particularly tired as a result of it having happened? Or how else might it affect them?

Julian Spinks

With periodic limb movement, often they stay asleep. However, with the RLs, main symptom, this need to move and the unpleasant sensation, it typically wakes people up. And one of the problems with RLS is that this is happening repeatedly through the night, so people are having to move either in the bed or often have to get up and walk around, and it interrupts their sleep. The result is they get sleep deprived, and the next day you have problems like concentration, you can start to get depressed, because sleep deprivation does that to that and very sadly, at the extreme end of things, we do get small numbers of people committing suicide because they can't tolerate having that symptom any longer

Steven Bruce

really, right? Well, that certainly puts this in context, because I said, What are the consequences for the patient earlier on. Have you got any ideas of the prevalence of the problem? And perhaps the number who are affected by very serious RLS?

Julian Spinks

Well, in Western Europe, the prevalence overall in the lifetime is about 10% so it's very high prevalence, but it comes down to the number of people who have it severe enough that they need help, they need to go and see a doctor or something like that. It's about two to 3% but that is still a very high prevalence, way ahead of other neurological conditions and sleep conditions, and taking you up into the sort of risk level of things like diabetes.

Steven Bruce

So what's the challenge for you then? I mean, do patients, do you think patients know that they've got RLS, or do they just think they've got a problem? Do patients come to a GP, or anybody else with things which they think might be RLS, which are not RLS. I guess I'm asking, what's the what's the rate of misdiagnosis, not seeking help because they don't know that it's a condition.

Julian Spinks

It's a real challenge for patients to work out they've got RLS often. It's when they see a television program or something else about it, or you have a friend or relative who talks about it, we used to have a big problem, because it does run in families between sort of 25 to 75% of standalone Restless Leg Syndrome, as opposed to being caused by other conditions, has a genetic element. And so you get people who say, Well, my mum had it, my grandmother had it, they don't think it's something that can be helped. When they do feel they need to get help, they meet a big gap. There's a diagnostic gap in that there's a lack of skill amongst clinicians, particularly GPS, in diagnosing the condition. And there's two linked other things, which is a treatment gap people are not aware of the more recent steps in diagnosing and treating and on top of that, when it comes to referring it seen mostly by neurologists in the UK, but also sleep specialists, and those are two specialisms where the wait at the moment is enormously long in my local area, they Have a triage process to see whether someone has severe problems, for general neurological conditions, and the waiting time for that is four months for the triage that's before going on the waiting list to actually be seen.

Steven Bruce

Gosh, and I was thinking that perhaps you are in a privileged position to some extent, in that you know about RLS. You've got you've suffered from RLS yourself, but as we were discussing before we came on air, I think you said that you don't know of any medical schools which teach specifics of RLS at all. So GPS, do GPS perhaps dismiss it as being a trivial condition, which you said earlier on, some might. Yeah.

Julian Spinks

They do sometimes dismiss it. Unfortunately, those GPs who have heard about it is mostly linked to some a few years ago, when a pharma company was raising awareness because they had a product to treat it. And as a result, there are some of my colleagues who think that it's a made up condition rather than a genuine condition, despite the fact it goes back to the 17th century. So that is a problem. It's easy for them to be dismissed. And as you said, medical school does not teach you about RLS. One of the things that RLS UK is trying to do is to lobby to get it onto the medical school curriculum. But it's a massive curriculum to start off with so it is very tricky. And we had one medical school say, Well, what else do you want me to drop so we can teach your problem? But given the level of prevalence, it is this problem of it being under recognized when you've got so many people out there who've got the condition,

Steven Bruce

yeah, does it often? Should I say? Patients often present with another problem, and only coincidentally, do you discover that they are also suffering from ILS. Now maybe, maybe a patient presents saying they're constantly tired, and then you have to look for the potential,

Julian Spinks

yes, and tiredness is a very difficult thing, because there are very few diseases that don't actually leave you feeling tired, but it means that sometimes it gets mistaken for just playing insomnia. And people get given hypnotics, which, of course, don't work very well and are very easily sort of you get tolerance, and you can be addicted to them as well. It is not uncommon, even when they go to their GP and say, I've got this problem. For it to be misdiagnosed. It could be diagnosed as things like leg cramps. If they've got periodic limb movement where you've got this forced dorsiflexion of the foot, is not surprising where the GP starts to say, well, that's probably a leg cramp. The main thing is that generally, RLS will not have you hopping around the bedroom like you would with a leg cramp. Although it's unpleasant, it's not as severe a symptom. The other thing is, it can be mistaken for things like peripheral neuropathy, anything else with nerve problems in the periphery, diabetic neuropathy and so on. And one of the difficulties we have is some of the treatments people have used actually worsen RLS. So if they think it's cramp and they give them quinine, that will make RLS worse, if they think it's something like radiated pain from the back, and they're given things like amitriptyline, nortriptyline, again, antidepressants, including the more modern antidepressants, tend to make RLS worse. And of course, if the person's got depressed because they're waking up at night, they may have depression, and then there's a really big challenge as to how you treat it, but it means there's lots of opportunities to misdiagnose RLS. But the other end of the spectrum, we do have to bear in mind that other conditions, like peripheral neuropathy, could be mimicking RLS, so you do need to ask some questions, do an examination and so on to see if you can detect anything else going on. Because I hate to say but when you examine someone with Restless Leg Syndrome, you're not going to find anything, because it's just not there, particularly during the day when you're going to examine them.

Steven Bruce

Yeah, and we've had a number of questions coming in here, so excuse me if I sort of backtrack a little bit. But PIP has asked, and you kind of addressed this, because pips asked whether you can get this in other parts of the body, not just in the legs. And you did say that it can progress to the trunk, to the upper extremities. Could it start in a different part of the body, or does it always start with restless legs? I mean, obviously by definition, presumably it must,

Julian Spinks

but sometimes it will start elsewhere, but actually it's relatively uncommon. And of course, one of the great mysteries is why it's your legs and not your arms. But as the symptoms get worse, yes, you get people where it starts to happen in the arms as well. And certainly I know a colleague, sadly, now departed from RLS, UK, who had it very badly in their stomach. And of course, it's very difficult to move your stomach quite the same way as you can with legs. And so people who have it in other places tend to resort to other things like rubbing and hitting and so on. And the amazing thing, some years ago, I saw a series of videos from different countries, and depending where you came from, as to what you use to hit your legs or your arms. And the UK, it tends to be rolled up umbrellas. In America, it's baseball bats, which I think are a little less sort of suitable. And in France, believe it or not, it's hair brushes. So there's definitely a difference in that. But yes, it can be in other parts of the body, and it can be at different times of the day, and that's why sometimes speak with more severe problems. If they haven't been diagnosed already, it gets missed by the clinician trying to find out what's wrong with

Steven Bruce

them. You'll see why it might be helpful to drop the restless legs title. If you can actually get this in your stomach, I'm finding it actually quite difficult to imagine how I would feel a need to move my stomach. I mean, do you get that?

Julian Spinks

And I'm very lucky I don't mine's only confined to my legs, and compared with a lot of my colleagues, actually, mine's relatively mild. I've occasionally had to use medication, lost the time. I just used sleep hygiene and so on. Although the really frustrating thing is that actually the more tired you are and the more you need sleep, the more likely RLS is likely to come along. I also have to be a bit careful about alcohol. If I have a small amount of alcohol, sometimes it'll make RLS better, but anything beyond a small amount actually makes it far, far worse. So if I go out to a nice party, I know I'm not going to sleep afterwards. I was

Steven Bruce

going to ask you about that, because if you look at the nice clinical, clinical knowledge summary, there are no NICE guidelines as far as I'm aware on this. It talks about sleep hygiene. It talks about cutting down on caffeine and alcohol and smoking and so on. And I was wondering whether there is actually evidence for that, or whether that's just that general advice that the NHS, NHS gives to everybody who's done well, cut down on the alcohol and the coffee and the

Julian Spinks

smoking? Yeah, I have to say, that's the sort of advice we give for everything, isn't it, really. But there is evidence certainly alcohol. You can see that sleep hygiene, which is all about having a regular sort of pattern to your sleep, making sure you're comfortable your pillows at the right height, that your room is not too hot or too cold, that can make a difference. And there are other things that people do before they go to sleep, and they can be and this is contradictory, but they can take hot baths, and sometimes they'll take cold baths. And it just varies from person to person, how that works, but we, I would always recommend people try non drug treatment first, because I'm sure we'll get onto the drugs, and there are problems with the drugs that are available. And so whereas if you talk to me 1520, years ago, I would have been very optimistic that we got the solution, it has turned out really to be a false dawn.

Steven Bruce

I guess you're probably not going to be able to answer this question, but have we got some sort of positive idea of what is actually causing the problem?

Julian Spinks

And that is the world's most difficult question to answer, I have to say again, 1520, years ago, we discovered that dopamine agonists, this group of drugs used for Parkinson's improved RLS, and it definitely does. However, subsequently, we've done a lot of gene studies looking at linking, and there's a greater link to iron, and particularly brain iron, and lacks in some bits of the brain to causing this, because it is largely a brain condition, although the symptoms are in the legs, quite why? We don't know there is secondary Ros, and that, again, tends to link into iron, because the times you get it are things like severe chronic kidney disease, and they tend to be anemic in pregnancy as well. We get this difference in iron, and also it can be linked to other conditions. In those cases, actually it's in a way better, because if you can treat the condition, then the RS will go away. Unfortunately, the case of pregnancy, the only treatment you've got to deliver the baby, and certainly RLS is not bad enough to have a premature delivery, but you can at least say to the woman, actually, if you can get through to the end of the pregnancy, the RLs should go away.

Steven Bruce

You talked about iron deficiency. I mean, Connor has asked whether this is a serum ferritin problem. Now I'm not quite sure the relationship between serum ferritin iron deficiency and, in particular, brain iron deficiency. Perhaps you can answer the question and address how you specifically increase brain iron?

Julian Spinks

Yes. Well, ferritin is a protein, and it's linked to iron stores, and so it's a very good marker for whether you are iron ripple or depleted. The difficulty is that if you look at the normal range for ferritin in most labs, it is based on anemia and that side, rather than brain iron. And so often, for example, my local lab, a normal ferritin starts at 20. However, in RLS, really, a minimum of 75 is needed to get that brain iron in there. Treatment is also a problem. Often people who have RLS don't seem to absorb iron so well, and so some of the RLs centers are now starting to do iron infusions, and they'll infuse people with RLS if their ferritin is below 100 so slightly higher than the 75 target, and that is more likely to work, but it is such a weird condition because it doesn't always work for some people, it is an absolute game changer. Suddenly, they're better. For other people, it makes no difference. And that does suggest that it is a syndrome rather than an individual disease. There are various core. Causes, and so no two people are completely alike, but certainly one of the things we're pushing for as a charity is to get more iron infusion available in the UK, because surprisingly, the one and only main RLS clinic in the UK, which is at King's, weren't offering iron infusions for some time. But if you're looking at Europe, for example, it's become much more standard,

Steven Bruce

given that you've commented on the high prevalence of the problem. I'm surprised maybe that maybe this is happening, but I'm surprised that I haven't heard more about Big Pharma trying to find a way to find a solution.

Julian Spinks

Yes, and they did look at it, and they came up with the dopamine agonist, which they already have for Parkinson's disease. And as I said earlier, it was fantastic. It worked, and I still use it as a diagnostic process. Give them one or two tablets, and if they come back and say it got rid of my RLS, then great. It's a good diagnosis. But we then discovered this condition called augmentation. And augmentation is a worsening of deterioration in the RLs, which is triggered by taking treatments for it, particularly dopamine agonists. So we had these people who were given the drugs felt they were absolutely brilliant, and then it came back far worse, and that is now a big problem. Interestingly, the nice clinical knowledge service still puts it as one of their first line medications. That's rapidly getting out of step, because if you look at over in the United States, is moving away from being first line, and there's a guideline being built over in Europe. And again, it's likely that dopamine agonists will disappear as a cause. And I think pharma have become, you know, having had their fingers burned, have become more reluctant to put the research in. But I agree with you that, you know, if you look at the other drugs, we've got, all the things we've got are things that were used to other conditions. And so the main first line drug at the moment, certainly in Europe and the United States, are the alpha two ligands, the gabapentin, the pregabalin group of drugs. They have their own problems, but at the same time, they don't cause the augmentation. And the other one that a lot of people are having is opiates. Unfortunately, the opiates that are best at RLS are the ones that we get told we mustn't prescribe because they're addictive. And so, for example, Oxycodone is one, and in the United States, they they use a lot of opiates, which we wouldn't really touch, the sort of things we use mostly for addiction, right?

Steven Bruce

Is there a balance there to be struck? I mean, if somebody's having unbearable RLS, surely it's worth giving them those opiates.

Julian Spinks

I personally agree, and I will do it. But I have had the phone call from the prescribing advisor at my local ICB, saying, Why are you prescribing these drugs? We had one patient, actually, who moved in who was on methadone, and everybody in the UK thinks methadone addiction, and so I prescribe it. I get a phone call saying, but you're not an addiction specialist. Why are you prescribing this drug? And I said, Well, it's a restless leg syndrome, and unfortunately, the prescribing devices don't know anything about it either. And so yes, it's it's a bit of a problem. We have to have a balance. Interestingly, the opiate doses, both methadone and oxycodone, are much smaller than are typically used for things like back pain and so on. If you are using it for that, and we don't seem to see, and I'm touching wood frantically, the degree of tolerance developing with it, probably because the dose is small, and it's indicating that it's not a pain relief effect, it's a different effect that's happening, probably on the brain to actually reduce the symptoms.

Steven Bruce

Yeah, we've had a number of people asking why it is that these meds make the condition worse, and Sarah has actually asked whether she was under the impression amitriptyline was actually one of the drugs prescribed for people with RLS, and maybe that's mistaken. I don't know. I guess my question in a little bit further on from that is, if they might make it worse, could they also cause RLS? I

Julian Spinks

certainly think it's possible that people have very mild RLS and may not be aware they've got it. They can get put on these drugs, and it gets worse. One of the most common queries we get at the charity, and I tend to answer, is my doctor put me on this antidepressant. My RLS is so much worse. What can I do? And there's a there's a big challenge, because most of the drugs that most GPs are familiar with for depression make it worse. How it does it is probably again, down to brain chemistry. On augmentation. There may be a degree of desensitization of receptors, so you're giving the receptors the equivalent of a lot of dopamine. They down regular. Eight, and eventually they down regulate to the point where they're no longer helping the RLS. Unfortunately, the danger then is, Oh well, I'll increase the dose of the dopamine and agonist, and the person gets better for a short time, and again it down regulates. There are some countries, particularly Sweden, like to give drug holidays where they people come off it for several months and then go back on. Problem is withdrawing from these drugs means you get the world's worst Rs, like a lot of sort of tolerance, tolerant drugs. You stop it and you're going to go through hell. And so there are a lot of people who haven't done it once don't want to do that again, because they say, Why do I have to go through hell for six months just to go back on the drug again,

Steven Bruce

yeah, I can see their point of view, definitely. What about other other supplementation, particularly vitamins and so on? Again, lots of people asking whether there are simple vitamin supplementations which might affect the problem.

Julian Spinks

Yeah, the main one, where people anecdotally say it helps is magnesium. And so if you put RLS and magnesium in, you'll find lots and lots of sites. The big problem is there's a distinct lack of decent research to say whether it works or not. But actually, all of it is, I tried this and I got better, or it's the company trying to sell you magnesium, which obviously can't be fully trusted. And again, it would be lovely if we could get somebody to take up doing some research. But of course, good quality research is expensive. Magnesium is relatively cheap, and a lot of these companies don't have a background in doing scientific research. Trying to get funding for RLS research is incredibly difficult. The European RLS Association, we actually set up a scholarship prize, and we have got a researcher who got a 10,000 euro prize to go towards doing research in RLS, again, very interesting, because she's looking at gut microbiome, which is a bacteria in your gut. And they have found some links where changing the pattern of bacteria improves, things like Parkinson's and multiple sclerosis. So it's a reasonable, logical thing to say, well, let's try it. Viralus. We don't know whether it'll work or not, so I tend to say to people, do try some magnesium. Don't exceed the recommended doses, because you'll get gastrin to startle upset is not very good for you, but it might be worthwhile trying, but I can't put my hand on my heart say yes, we've got good evidence. This works. It's

Steven Bruce

quite a useful takeaway for the audience today, isn't it, because it's something that we could state, and while they're waiting for an appointment with somebody who can do detailed investigations, there is anecdotal evidence that magnesium supplementation would be beneficial, so it's worth trying because it's not expensive. So yeah,

Julian Spinks

yes, I'd agree on that

Steven Bruce

somebody called Mt says, If RLS has a brain based etiology, are there certain rehabilitation approaches that have shown merit? Could you talk pathophysiology briefly, high level summary, anything related to cortical mapping, spreading or something else, or wholly uncertain cause, there's a bit of a mishmash of concepts in there. But again, I think it'll be interesting. What actually is it possible to see any changes anywhere in people who've got RLS, whether it's changes to the nerve fibers themselves, or brain mapping,

Julian Spinks

there's surprisingly little when you come to look at it, people are starting to do some sort of fancy brain scans and using contrast and so on, to see what's going on. And we're hoping to get some funding to do functional MRI scanning, this thing that they can do, particularly with pain, where they can spot where pain is firing up in the brain. And so it would be lovely if we could do that to see whether it makes a difference. Do a functional MRI on someone

Steven Bruce

who's sleeping. They've got to be able to sleep through the bloody noise of the MRI, apart from anything else,

Julian Spinks

yeah, that, that is the big problem. And so what we're looking at is seeing if we can find people who have the very severe end of RLS, who are getting it all day, every day, where, with a bit of luck, they can tolerate a half hour session in the MRI scanner. And you know, I have been in one once, and it was the most unpleasant experience of my life, I think, because I'm claustrophobic. But if we could get people to do that, we might be able to see things switching on and off when it comes to sort of rehabilitation and so on. I said earlier about some hot and cold bars. And people use compressors as well. Some people do things like leg stretching before they go to bed, similar to the way people do with cramps. That seems to make a difference. I personally found that when I started to do exercise, started going to the gym, my RLS got better. But I can't say there's any scientific background to that, but I do think that if you've got sort of healthy muscles and limbs and so on, then. It may be that your ability to respond to the calls when your brain tells you you've got to move your legs may be not as disruptive.

Steven Bruce

Yeah, I'd be interested to know from any of our audience whether there's any role for acupuncture or other things, maybe even 10s in helping relieve the symptoms in this. I don't know if you're aware of them.

Julian Spinks

There have been some products, one of which are basically foot wraps that sort of squeeze the feet. There are other things that sort of vibrating processes, either just the machine vibrating or or using sort of electrostimulation to make the muscles vibrate. I don't think that it's actually treating RLS, but it's similar to these people hitting their legs or stimulating them or scratching them or whatever, that it's almost like a counter irritant that will turn down the RLs and do it that way. But given the problems we have with drugs and so on, I think the more research we can do into alternative therapies that don't involve using medication actually pretty good, whereas, say, 1520, years ago, go, Oh, are you bothering all this stuff? You know, you give them a drug and they'll be better.

Steven Bruce

So when you when you see a patient who complains of this syndrome, who is your first point of referral, would you be sending them to a speech sleep expert

Julian Spinks

in my area, it would be a neurology in other areas, it may be a sleep clinic. The one thing about sleep clinics is that they can actually put people on in the sleep clinic and monitor what's happening at night, and see half of the waking up. And if they've got periodic limb movement, they can detect that as well, which which is good, but there are so few sleep clinics in the UK, and a lot of them are almost totally dedicated to sleep apnea, that it is tricky. Neurology. We really don't have enough neurologists. And when I go over to conferences over in Europe, they have the luxury of having so many specialists in the field. At one point, I think about 10 years ago, there were more sleep clinics in Berlin than there were in the entire UK. So it gives you an idea of the different amount. But a challenge really is knowing who genuinely has knowledge to treat RLS, when as a NHS, GP, I go on to the electronic referral system. I can type in conditions, and if I put in RLS, it'll come up with a list of local hospitals and so on, where there is a consultant who says they deal with RLS. Unfortunately, most of them, it's almost like they were the last ones who to put their name down. And so they got RLS, which nobody else wanted to take, rather than having expertise, we are on a European basis, trying to set up something called the expert finder, which is a website where you can go in and locate clinics which have somebody who genuinely has expertise in RLS. But it's been quite tricky to do, because you suddenly come across sort of multinational GDPR type problems of how you can give information out. Other problem is that the small number of specialists who genuinely have an interest are snowed under. So we say to them, Look, can we put you on the expert finder? They go, Oh, please, don't we put me on I've got more patients than I can cope with already.

Steven Bruce

Yeah, I can see that there's a real challenge here, isn't there? Because even if you can find the experts, if the prevalence is so high, there's going to be a hell of a queue of people waiting at the door of that particular expert. And we've had sleep experts on the show before, and again, it's always about sleep apnea, so they'll be diverting their resources that way. I've had a question from someone. I don't know the name of this person. They're known as 512, according to my records, it says that they've heard that the supplement GABA GA can be helpful with RLS, but it's not available in the UK, only online from the States. I don't know if you know about it, but if you do, can you comment on whether it's safe or not?

Julian Spinks

I haven't heard very much about it, certainly not available in the UK, and currently it's not in any of the guidance. The thing we follow at the moment is something called the Mayo Clinic algorithm, which is worth having a look at, because it tells you sort of the current state of things. But the American Academy of Sleep Medicine, I think that's right, yes, are also going to be launching a guideline. They've gone through consultation, so the final version should come out in the next few months, and I'm going to certainly be recommending that clinicians in the UK follow that guidance whilst waiting for the UK to catch up, because unfortunately, it is difficult, because nice sort of says Not everybody gets augmentation, Therefore we should still recommend it, but just warn people it might be a problem. And I don't necessarily feel that's the right approach, and I'm someone who's actually been involved in writing NICE guidelines, so not on RLS, I hasten to say. But you know, I know how nice works, and it is quite slow moving and very conservative when it comes to recommendations. Patients. So the CPS, as you say, is not a full nice guideline, and we have again approached nice to say, can we have you do a full blown guideline? Because that would actually give a much more robust guide, especially to secondary care colleagues, because the clinical knowledge service is mostly used by GPS. Well,

Steven Bruce

I was interested. You mentioned that. As I said earlier on, you just mentioned it. There's only a CKS, a clinical knowledge summary on on the nice website. What weight does that actually have in guiding GPS or other practitioners in dealing with any problem? But in this case, RLS,

Julian Spinks

it, it has a degree of weight, but nowhere near the same as a full, nice clinical guideline. It's developed by a group of people who have an interest at Saad, and they look at it. They've got pharmacists and various other people who write it. But if you compare that with the sometimes over three year process to come up with a full, nice guideline, the ones I've done well by the time we get to the guideline development group, there's two years left in it, and there's really complex searches done and a lot of work done to try and come up with the rest, you know, the perfect guidance. And I would much prefer to have that now that's being mimicked by the European Academy of Neurology, who are doing a guideline on RLS, and interestingly, they've just put it back slightly, because they're moving to looking at sort of minimal clinical significance as opposed to just statistical significance, because it's a problem. If you've got something that's statistically significant but makes so little difference, nobody can notice it. What's the point? So they're moving on that. So we're getting a series of them coming, and it's slowly moving towards the UK, but nice is pretty busy with guidelines. And of course, it's having to redo existing guidelines. I've done two redos in urology, which is my clinical interest area, and so again, each of those still taking three years to do. We did one guideline on meshes, pelvic meshes and things, and that was enormous amount of work and stretched out to only four years.

Steven Bruce

Well, I suppose, if anything is slightly reassuring that the CKS was revised in February this year. So that's relatively recent, even if it's not quite as powerful as a full blown guideline. Sally asked a question earlier on about whether RNs is always bilateral.

Julian Spinks

I have almost always found it to be bilateral rather than unilateral, and that probably reflects the fact that the origin of the sort of symptoms and so on is the brain rather than the limbs. And I think if you have unilateral RLS, you have got to really look very hard to make sure it's not some other neuropathy or other condition, but normally it is bilateral. Okay?

Steven Bruce

Robin is a fellow sufferer and is well known to us on this particular show, but he asks if there's a link with NMSP, neuroesthetic, musculoskeletal pain, either as an aggravating factor or as a cause. Robin says he suffers from episodes of insomnia from a historic brain injury, which he says accounts for a lot. But he's noticed that his RLS is worse for lack of sleep. I suppose there's a bit of a chicken and egg there. Isn't there. I mean, RLS would cause him lack of sleep as well as the other way

Julian Spinks

around, absolutely. And as I said earlier, that's the problem I've always faced, is that when I've had a really tough day and I'm feeling very tired anyway, almost certainly that's the night that I'm going to get the IRS, which means I wake up the next morning, or maybe stay awake the next morning and feel even worse. And if you're not careful, it keeps building. And in the past, that was one of the reasons for using hypnotics, sleeping tablets and so on. Was more to try and get you to sleep the next next night. But the trouble is, hypnotics help you get to sleep. They don't keep you asleep, so the RLs will still wake you up. So the danger is, you just wake up feeling sort of groggy and half out of it.

Steven Bruce

And yet, I noticed on the the CKS web page that Z drugs, I think they're called, which are prescribed for insomnia, rather, they're still part of the protocol.

Julian Spinks

They are, and it's it is an interesting balance, the shift between the different drugs, the different points in the treatment are there, if it is people who predominantly have sort of insomnia and they don't get the legs and so on.

Steven Bruce

Now I'm not sure whether you can still hear me, Julian, but you've frozen on my screen and your audios disappeared. Here we are. We're back again.

Julian Spinks

Oh, right, goodness, so that I. Just about to reconnect, right? Yeah, I don't know where I got to, but I was saying the Zed drugs are quite useful if there's there's not a lot of pain and other things. But you have to remember that they don't work for very long just with any other insomnia. The Z drugs and the benzodiazepines work really well for a couple of weeks. So so for a couple of weeks, after a month, actually, they're not working at all well, and that that's why you get people who end up on increasing doses and increasing tolerance, so they're there. I mean, they could be useful people who get it on an intermittent basis, where they've just had a bad night and they just like to get a better night's sleep the next night. But as a long term treatment, they're not really that effective, right?

Steven Bruce

Well, interesting, too. The sleep experts that we've had on the show have said that those anti insomnia drugs, they, as you said, they put you to sleep, but they don't give you good quality sleep, and so you don't necessarily wake up well rested afterwards. And again, that might be part of the problem. I mean, Robin did ask whether neuro, neuro, esthetic, musculoskeletal pain, could be an aggravating factor of a cause that was his first

Julian Spinks

Yeah. I mean, almost certainly the two would add together, because there's some overlap in symptoms, and it is. It's difficult to know, because there are quite a lot of conditions where you're more likely to have RLS or RLS is worse, where the one causes the other, I think is tricky, but a lot of the correct diseases, it tends to be worse in them, including things like diabetes. I'm a diabetic myself, but it's very difficult to see where there's a link between the two. And maybe it's just simply that if you're feeling ill and rough and you're not right, then the symptoms of RLS will tend to be be worse. And if you're half awake already because of other conditions, then RS will definitely wake you up.

Steven Bruce

Yeah,

you talked earlier on about leg movements during sleep. Billy Anna has asked about constant calf muscle fasciculations and whether RLS is related to that. If so, are the perhaps the iron infusions that you talked about worth a try for those as well.

Julian Spinks

In general, you don't get facilitation with RLS, the movements, apart from the the periodically movement of sleep, which is an automatic thing, most of the movements you're doing in RLS is voluntary. You're actually waking up and having to move. And circulation is normally individual, little muscle bundles going off one at a time. They're more likely to be a link to neurological conditions and nasty things, like most Urine Disease and so on. Although, having said that, I do get it in my one leg, but that's a result of nerve root irritation when I managed to put my back out some years

Steven Bruce

ago. Can recommend some good osteopaths and chiropractors

Julian Spinks

for you? Well, all I can say is that actually making your own bread is dangerous, because I put my back out lifting a one kilogram bag of flour off a supermarket shelf. So doesn't take much,

Steven Bruce

yeah, well, you know, we're very familiar with the trigger. The trigger being picking up a sock or something like that, but it's obviously not the original cause of the problem. But that's a bit of a digression. Sophie wants to know if there's a link with ADHD. Apparently, she's got two patients that have both that and RLS.

Julian Spinks

I'm not aware of there being one. And of course, ADHD is also relatively common condition. And so if you've got two common conditions, the chances and overlap are much greater. But we don't have a lot of people in the association who have it. The other thing we have at the association is something called Health unlocked, which is a discussion forum with about 10,000 members worldwide. And so I think we would have spotted that coming in on that that basis,

Steven Bruce

right, okay, Elspeth asked, What about overuse of legs, running or walking a lot? Does a lot of exercise provoke? Cause, aggravate? RLS.

Julian Spinks

In my case, I was, I was over in Germany recently, and my friend likes to walk her dog, you know, like 10 kilometers at a time. And at times, I was finding my neurosis worse. But I do wonder whether it was just simply that my muscles were tight, and so when I did wake up, it just just felt worse. But in general, exercise does improve things, but I think, like most conditions, if you're going to do it to an extreme, then you're more likely to get sort of other symptoms to go with it.

Steven Bruce

Okay, again, it all sounds as though it's it reflects the lack of knowledge of what actually causes the problem, doesn't it? I mean, I'm sure there are lots of things which are associated with it one way or another, but working out causal factors is much more difficult. Alison, no, no, sorry. Alison says her husband has RLS or had RLS when he was on sertraline, which stopped when the the ad was stopped, when he restarted the search. Releen, the RLs returned within a few hours of taking the. First tablet

Julian Spinks

that is, it is absolutely a common thing that happens. This is what we get. We get people who say, you know, I have depression. My doctor put me on it was terrible. He took me off because he did. He wasn't convinced it was that. And then he put me back on it, and it was back there. Are one or two drugs which are less likely to cause it. Unfortunately, they tend to be drugs that are very rarely used in general practice. One of and for example, Bupropion, which people in the UK tend to know as a treatment for smoking or smoking cessation, is an antidepressant, but it's not licensed for depression. In the UK, it's only licensed for smoking cessation. So I have people go to their GP saying, Can I have this? And understandably, the GP says, No, you can't. It's not licensed. So, but GPs

Steven Bruce

are allowed to provide prescribe things off license. Aren't they off label? They

Julian Spinks

are, but they are. But unfortunately, a few years ago, the General Medical Council came up with a bunch of advice, which says, if there is something which is on license, then you should prescribe that in favor of something that's off license. So the GP will say, Ah, well, you know, I've got Bupropion which is off license, or I've got another antidepressant, I better go for the one that's on license. Or, you know they'll they'll say, Well, if it's RLS, I'll go for the licensed drugs. And the licensed drugs are the dopamine agonists and oxycodone. So inevitably they end up going towards certainly, the dopamine agonists are not good news. Oxycodone, slightly less problematic. But again, GPS tend to overdose on that and not use the doses. I

Steven Bruce

guess it would be easy to criticize GPS for that, but I always reflect on the fact that you as a GP, any other GP, you've got what, your 10 minutes to diagnose a myriad problems that might be causing the symptoms and work out which of the many drugs might be useful. If you don't guess in, you know, in a normal medical school, the respect of the GP,

Julian Spinks

I spent my life because one of my other hats was, I've been the chairman of the local medical committee representing GPS, and I spent my life saying exactly what you've just said. The curriculum, the amount of things we have to cover as a GP is enormous. Inevitably, people have a degree of sort of speciality as to what they do and so on. And if you've never been taught it, how do you even know? Does that have it in the back of your mind that it might be a diagnosis to consider? GPs are pretty good at looking things up, because there's no way I could remember everything about everything, but at the same time, I've got to have at the back of my mind, Oh, yes. It could be that. Let me have a look and see, yeah.

Steven Bruce

And equally, the only way you could look this up, well, through the NHS sites, would be through the clinical knowledge Summary The CKS, which wouldn't have mentioned that anti smoking drug that you just mentioned, so there'd be no indication there that it might be useful.

Julian Spinks

Yeah, yes. And that's why we have leaflets for patients, and also we put them in direction, things like the mayo algorithm, and say, why not take it along to your GP and say that naughty Doctor Spinks is giving you trouble. And try reading this, and it might actually help you a bit. I would love to have more training sessions for GPS, but we're a small charity. We don't have enormous funds to be able to do that, which is why it's wonderful to be able to come on this, this broadcast today, and actually teach a new generation of people that are or less well,

Steven Bruce

I think they'll find it really useful. Because again, I mean, what do we do as a physical therapist when someone comes along with a problem which is clearly very distressing and we don't have a ready solution. Goulam has asked about whether he whether you think strain counter strain technique, what might be useful. But I suspect you might not be familiar with strain counter strain technique, because it's a very niche

Julian Spinks

Yes. This is my GP thing, where I have to reach the limit of my knowledge, and I have no idea. I'm afraid on that one,

Steven Bruce

yeah, and it's a very unfair question to put to you, but I mean, it's, it's one for the audience generally, if you, if you know something, you've got some experience about strain, counter to counter strain, then you know, sending your your thoughts to us. Final question, perhaps, sir, a final question from Kelly, who says, Is there a link to an imbalance in dopamine levels. And you talked about dopamine earlier on, but simple answer to that

Julian Spinks

one, there probably is a relative imbalance. But dopamine is not the primary cause. When they've done gene studies, which they're doing a lot of recently, the one thing that has not come up is linked to dopamine problems. So it's a weird thing. It's something you can treat with but it's the same way as saying that, you know you can treat headache with ibuprofen. It doesn't mean that Ibuprofen is the cause of all headaches,

Steven Bruce

right? Well, it's very kindly to give up your lunchtime for us today. Julian, thank you so much for that. It's a really interesting topic, and. I think we'll probably hear a lot from our members about what they can now do for their patients. So again, thank you very much for your time. It's been a pleasure.