

## Airing Pain Programme 92: Diabetic Neuropathy

*With 80% of amputations preventable with the proper care, we discuss diabetic neuropathy & why we should treat our feet*

*This programme was funded by a grant from The Schuh Trust.*

*There are around 4.5 million people living with diabetes in the UK, and every day more than 20 leg, foot or toe amputations are carried out as a result of diabetic neuropathy. This is particularly shocking, as four out of five of these amputations could have been avoided with proper care\*.*

*People with diabetes are often bombarded with advice on diet and exercise, however as with any long term condition it can affect all aspects of life. In this episode of Airing Pain we talk to Linda McGlynn from Diabetes Scotland and clinical specialist physiotherapist Ben Davies.*

*Linda explains how diabetes affects the nervous system and why it's so important to look after our feet. Ben describes some the results of his research into pain management for those with diabetic neuropathy, and why diabetes specialists left feeling "clinically impotent" should look towards the pain community for better treatment models.*

**Paul Evans:** This is *Airing Pain*, a programme brought to you by Pain Concern: the UK charity providing information and support for those of us living with pain and for healthcare professionals. I'm Paul Evans and this edition's been funded by a grant from the [??] Trust.

**Linda McGlynn:** There are a number of amputations, both minor and major amputations, across the UK, and 80% of those could be avoided with the right care and attention to people's feet circulation and management of diabetes.

**Evans:** Diabetes is a serious life-long health condition that occurs when the amount of glucose - or sugar - in the blood is too high because the body can't use it properly. And, if left untreated or mismanaged, high blood glucose levels can cause serious health complications.

This is how it works: glucose is the fuel our body cells need to keep going. But in order for those cells to receive the glucose, they need to be unlocked. And the key to unlocking them is a hormone create in the pancreas called insulin. If that key, insulin, is missing or unable to unlock the cells, diabetes occurs. And there are two types of diabetes: Type 1, which counts for 10% of people with diabetes, is an autoimmune condition, where the body attacks and destroys insulin-producing cells. In Type 2 diabetes, the body doesn't make enough insulin or the insulin it makes doesn't work properly. Those with either type of diabetes are at increased risk of stroke, heart disease, blindness, neuropathy, amputation - a whole raft of physical complications, as well as the psychological ones, anxiety and depression, that are associated with all types of long-term condition.

In this edition of *Airing Pain* I want to focus on the physical complications, in particular painful neuropathy. Ben Davis is a clinical physiotherapist working in primary care in the Bath and north-east Somerset area. His doctorate research on painful diabetic neuropathy explored different ways for people to cope with the condition.

**Ben Davies:** People develop diabetes from many causes. Some people have a genetic predisposition to it - that's Type 1 - other people develop it over life for other causes. Diabetes is characterised by a difficulty in regulating your blood sugar levels, essentially, and over time if that regulation is not so good, people develop nerve problems.

I think people are quite aware that people with diabetes can have numb feet, a loss of sensation: you can kick your toes and not feel it, you can have stones in your shoes but not feel it... For about ten percent of people you develop painful neuropathy, which is where you don't have the pain that protects you from damage, but you do have the presence of a pain that is burning in quality, pretty unpleasant, comes of its own accord, often worse at night, and can be really debilitating. And that's the group of people that my research has been focused on.

**Paul Evans:** So why does that happen?

**Davies:** The full answer, I think, is actually not fully known. The contributors to why this happens are the blood sugar levels, essentially leading to a stress on the nervous system right at the fine nerve endings out in your toes, the longest nerves in our body end up in our toes and our feet. There's a contribution from a lack of oxygenation in the blood, leading to a lack of oxygenation in the nerves, changes in how those nerves get energy - so the function of the nerve alters.

But there are also contributors from the spinal cord. When those nerves come up your leg, into your spine, there are junction points, and there's a whole, kind of, cascade of events at the spinal cord level of how danger messages or messages in the nervous system are, or are not, carried on into the spinal cord and then higher up into the brain. Does the brain pay attention to the leg, not pay attention to the leg? It's a complicated process that leads to this pain problem.

**Evans:** Ben Davis. Linda McGlynn is the regional engagement officer for Diabetes Scotland. She's speaking with Pain Concern's Rebecca Dyce.

**McGlynn:** Neuropathy is, basically, damage to those fine nerve structures that send messages down and up from the brain. So it is a disturbance in the functionality of those nerves. You could have a *sensory* neuropathy, which means your feeling is diminished - numbness - and what then happens is, if you've got numbness in your feet, if you walk in your bare feet and stand on something and you get it infected [if you have diabetes and] your blood glucose levels are high, [the diabetes] will increase the chances of you developing an infection in the wound and it takes longer for that to heal.

So, if you have neuropathy and you don't know you've stubbed your toe or stood on something or you're not aware that the heel of your shoe's been rubbing and you've got a blister, then that blister gets infected. What then happens is very, very quickly that becomes black, really infected, and it can happen really very quickly. And what happens is you will then see a podiatrist or a surgeon and it can't be saved, so it results in either a minor amputation, which is a loss of a toe or a few toes, or it could be something more major, either below knee or above knee amputation.

**Paul Evans:** I have Type 2 diabetes and it was explained to me, perhaps over-simplistically because I am a simple person, that it's like this sugar in your blood, sugar in a liquid makes it treacly and thick. So I can understand how that affects the circulation, because - again simply - if the thick treacle blood can't get through your veins and arteries, then it starves them of blood. But you can't starve the nerves through sticky blood, can you?

**Davies:** Oh you can. Your nervous system sits in your body, if we took it out it weighs about two percent of your bodyweight, yet your nervous system is always on, always requires energy, and actually uses twenty percent of your energy output. So nerves, particularly the brain, but nerves right down to your toes are highly active in using energy. And they have a very intimate blood supply, nerves have a blood supply within them which we can block. If you've slept on your arm and you have a dead arm in the morning, or your buttocks are numb having watched a film, that's an everyday example of your nerve function having been lost because you've blocked blood supply for a while. You wake in the morning with a numb arm, you shake your arm around for five minutes, that feeling comes back. But that's an everyday example where nerve tissue lacks blood supply, and you develop a numbness. Now suppose we take that to diabetes, that thick blood - your idea is absolutely right - that thick blood struggles to get through the very fine capillary bed, the tiniest blood supply vessels that are inside the nerves. So those nerves right down your toes begin to become numb, to lose their function.

**Evans:** So the nerves that need that energy get starved of [it].

**Davies:** Absolutely, yeah. I mean, there's a lot of complex bio-chemistry behind it, but as a high level message that's the critical thing.

**Evans:** Physiotherapist Ben Davis. Linda McGlynn:

**McGlynn:** Neuropathy is very complex, as I said you've got sensory, then you've got autonomic. What autonomic in neuropathy does – these are the nerves that look after your heart, your lungs, your stomach – if you have neuropathy in any of the nerve supply in maybe the stomach then that can cause slowing of the emptying of the stomach, that's what we call gastroparesis, and people can have vomiting. It can affect the lower part of the bowels so people have diarrhoea, it can cause erectile dysfunction, loss of libido, bladder. So that's the autonomic; these are things that we have no control over but they are there and neuropathy will affect those.

And you also have motor neuropathy, so for the movement of the muscles, the messages going down to the muscles may well be not getting there. So they're the three classifications of neuropathy.

**Evans:** So I - and I'm not sure if this is countrywide but it's certainly in my health authority - I have a check up every six months for my diabetes and one of those checks is sticking what I would consider a tuning fork on my feet to see if I can feel it. That, presumably, is where neuropathy is picked up.

**Davies:** Absolutely. Vibration sense, as a function of the nervous system, is one of the first qualities that's lost. So if you were to go home this evening, lie on your arm for a few minutes,

then try a tuning fork on your thumbnail, after a period of time you would not sense that tuning fork. So vibration sense is one of the first functions that's lost. Your practice nurse, specialist nurse, podiatrist, GP perhaps will use tuning forks and sometimes a little filament that bends under a certain pressure; and they'll push that onto various points on your feet. If you can identify, if you can feel that pressure, then that's good. If you can't feel that pressure there's a little scoring system to suggest a level of loss of nerve function - a developing neuropathy.

**Evans:** Ben Davis. Linda McGlynn again:

**McGlynn:** Some people, by virtue of the fact that they have no feeling— what we see is— some people don't know this but they say 'When I'm walking it feels as though I'm on cotton wool.' If they've got that bit where they don't know where they're putting the foot - so from the sense of the nerves to the brain and back again on a feedback loop - so if you move your foot you know you've moved your foot, but if you've got motor neuropathy you might not know that, the muscles might have changed or moved. If that's the case then you don't know where you're placing your foot, it can feel like cotton wool. People can actually trip up fairly easily, because they don't know there's a change in their [??] region, from carpet to wood floor etc. And everybody's different.

When it's painful it's really severe, pins and needles, it's that burning sensation. Sometimes people can get really severe shooting pains and it's so severe that it takes your breath away. And if you're getting those constantly, especially in the evening or when you go to bed then you can understand how difficult it is, how depressing that could be, and how it can impact on every aspect of your quality of life.

**Davies:** It's hard work, managing persistent pain. People usually have some level of worry about that pain, some level of social isolation, perhaps not being the person they expected to be - the partner, the parent, the grandparent, the friend - so they'll come with other stuff.

Now I'm not a psychologist, but we would use, perhaps, psychologically informed physiotherapy - I think it's important that we raise issues like stress management strategies, we raise sleep strategies, we raise the impact of feeling sad about the situation you're in or worried about the future. If we can raise those things *earlier* in someone's pain journey, perhaps they can use *more* strategies to manage the impact of that pain, and do so more effectively, than if they were to simply rely on a single exercise, a single drug, a single injection or surgery. So we're trying to broaden the toolbox that people have for managing pain.

**McGlynn:** It's about managing those symptoms, making sure people are comfortable. So that [means] looking at pain relief, and the treatments can be anything from a mild analgesic such as paracetamol, more powerful ones such as Gabapentin, Pregabalin, just looking at how we can help people manage the pain. TENS machines... If someone's got painful neuropathy and they've maybe got slight weaknesses in the muscles, it could be that they actually get physiotherapy to actually strengthen the muscles and the joints, but they would still need the analgesia.

So it's very much around if it's a painful neuropathy it's managing it, and it's about how do you manage intractable pain. What we say to people is, it's about having that discussion with the healthcare professional to see what's the best aspect for them. When it is so severe that people

are referred frequently to pain clinics for severe pain management and again the processes for that are different for everybody...

**Evans:** That's Linda McGlynn, regional engagement manager for Diabetes Scotland. Unfortunately, referrals to pain clinics and pain management programmes are not as frequent as might be expected. Ben Davis again:

**Davies:** My PhD research focused on how people with painful diabetic neuropathy are rarely seen in multidisciplinary pain programmes. So, a multidisciplinary pain programme, physios and psychologists, has two central tenets to it: One is physical activity, helping people be as fit as they can be. The other is psychological coping: How do we help you manage that low mood and worrying? Psychological issues. Yet, people with painful neuropathy rarely come into those programmes and we didn't really know why.

There is some evidence that people when they *do* come in with this burning pain, spasmodic and unpredictable, they don't necessarily get the same benefits that someone with back pain gets, so it could be that the programmes as they currently sit are not quite formulated right, they haven't quite got the right techniques in for this population. I went and interviewed 23 people with this problem in the UK, some face to face in the Bristol area, some over the phone who had seen my adverts in Balance magazine (the Diabetes UK magazine) and I asked them, "What does this problem cause you? What are the impacts of this problem? How have you experimented with managing this pain problem, what have you tried? What would your view be of physical activity for managing this pain problem? And what would your view be of psychological coping for this problem?" - Y'know, How acceptable does this sound? Does this sound like something I'd like to be involved in or does it sound like nonsense?

**Evans:** Can I hazard a guess as to one reason why there could be this difference there? You can shoot me down immediately. Could it be because the diabetes departments, like many other departments, are self-contained? They're over here on my right, and pain management programmes, the pain doctors are over *there* on my left, on the other side of the hospital or even in a different hospital. And, uh, never the twain should meet.

**Davies:** Yes. (*laughs*) Very simply, yes. I think that's a big issue. When people in the diabetes world, so people with this pain problem, come to the diabetes clinics this problem is recognised. There are recognised pharmacology drug approaches for these pain problems. There's good evidence that these four drugs have a role to play. The problem is they don't help everybody. One of the specialist diabetes nurse that I interviewed used this very nice phrase, she said "*When we've tried all the drugs and it's not helped, and medics have tried all the same drugs and they've not helped, I feel clinically impotent. I have nothing to offer.*" Because as you just said, the diabetes world perhaps doesn't have that much exposure to the pain management world. There are strategies settled in the pain world that could perhaps be translated to the diabetes world.

**Evans:** Or even a physical pathway between the two departments.

**Davies:** Well, you can't refer somebody to something they don't know about

**Evans:** Exactly.

**Davies:** Yeah.

**Evans:** So I think we know what some of the answers might be. What is being done about it, if anything?

**Davies:** I interviewed this group of people - just to say I also including clinicians about their point of view, diabetes specialists and pain specialists, but to stay with the people with this problem - there is a huge range of impact.

We had 58 kinds of impact in the way this problem, PDM, affected their lives, and that's a really broad range! And it was much broader than the evidence had highlighted up to that point. There were six priorities that people highlighted: sleep, worry about physical activity and physical fitness, there was anxiety and depression in there, numb feet and walking. But out of these top six, pain wasn't an issue that they prioritised. Among those 58 statements, there were four or five that required strong pain statements like "PDM brings tears to my eyes in the morning", but those were not prioritised by people. So that was the first interesting thing.

They had experimented with a wide variety of strategies, from having fish pedicures (putting feet into water), alcohol, cannabis extracts... One chap I remember he said he walked on stinging nettles in the fields near his house because that gave him, perhaps, a distraction. So people had experimented with a wide range of things themselves, generally without success.

Thinking about exercise, physical activity, some people were really keen for it, they wanted advice about exercise, they wanted to be able to keep walking or cycling, but there was a healthy degree of scepticism around exercise: "How would that help my nerve damage? How would it help my diabetes?"

Similarly with the idea of psychology, some people had been to a psychologist, some people had been through a pain management program for their back pain and felt that was irrelevant, but lots of people sort of said "Well, why would talking to somebody help this pain problem? It's my feet! It's the nerves in my feet." They didn't see the connection between managing stress, managing mood, and the pain experience. So it wasn't really clear that we could simply define a slightly varied pain programme, we'd probably need to explore some other avenues first.

**Evans:** But education comes into it, doesn't it? "Doctor, why are you sending me to a head doctor when I need a foot doctor?"

**Davies:** Well! That's a very good statement. And it's a statement that's highly entrenched in medical management. I could take it back to Rene Descartes, seventeenth century French philosopher. He argued that the mind and the body were separate. I think at the time he argued that [we should] give the body to science and leave the soul with the Church.

Now, that was useful and it allowed science to move on, but it creates this split between mind and body which is false. I could ask you to sit there and imagine the most embarrassing moments of your life ever and you would have a physical response in your body. So there is an intimate connection between mind and body and this idea that minds and bodies are separate entities - well, they're not! If you're a person in pain, you're a *person* with pain and that affects your body, your mind, your psychology, your relationships, your societal interactions... It knocks-

on in complex ways. So yes, diabetes and pain are different, but they're also present in the same person.

**Evans:** Yes, well, we both know that, but how do we get that over to somebody who is a skeptic who wants his foot mended?

**Davies:** With all pain management approaches you can't force people to any kind of strategy. You can educate or you can highlight perhaps a dissonance in their very structural ideas of pain. They have probably had times in their lives when they've had damage but not experienced pain, so the idea that damage in your feet has to equate to a pain experience is not really true. We can offer, as best we can, and self-management requires that person to then take ownership of the advice, but that person's an autonomous person: if they don't want to that's their choice.

As clinicians I think we do our best to motivate, to make it relevant to that person and highlight the improved quality of life that might come out of employing these strategies, but I'm also very aware that it's hard work applying multiple strategies at the same time to maximise your quality of life. And many people want the pill - as I'm sure I would if I had an ongoing persistent pain problem. I would want the simplest treatment management possible. The reality is, sometimes people have to go through a period of time and realise there's more to that than a simple pill.

**Evans:** And we go back to what pain management programs are all about: it's getting people to believe that their quality of life will get better, that if they address issues of thought, mind and deed that's part of the pain management program. So, how do we get the pain management program into diabetes?

**Davies:** I mentioned that we had 58 impacts of this problem. A later study that I did was to take those statements, put them as part of a questionnaire survey on the internet, which was distributed on Diabetes UK and I posted it on peer support groups in various diabetes forums. The survey ensured that people had this painful neuropathy problem. It asked about the frequency of the experience of these problems, but the thing that I was most interested in was - we gave people the opportunity to select and prioritise what they most wanted help with. Out of these 58 things choose ten and re-order them, and put them into your priority list for better pain management. And there were 6 things that were captured among the subgroups (men, women, people with Type 1 or Type 2 diabetes, high an low pain levels). The top universal first priority was sleep. Now, they'd never had sleep advice. Sleep can be affected by pain, but the lack of sleep makes pain worse, it goes both ways. And you can suggest sleep management strategies to somebody in pain and if those strategies can be enacted by that person, when their sleep improves their pain will improve, along with their quality of life and other metrics. So the first priority that all these people in my survey wanted was advice on sleep. Could we bring back, just this little piece of information, back to the diabetes world? Could the diabetes specialist nurse have a sheet on sleep?

**Evans:** That's really interesting, because people with diabetes are bombarded with dietary instructions, but there's far more to life than just eating!

**Davies:** *(laughs)* There is, yeah!

This is where the biology becomes complex. If you don't sleep well, that's a stressor on your system, and stress tends to be pro-inflammatory, so it adds to the inflammation that's part of the

development of neuropathy. And stress affects your insulin pathways. So, to my understanding, the diabetes world is aware of the fact that you've got to manage stress, balance life stressors - but not sleeping is a stress! So we do need to have some language, some advice, some strategies to perhaps suggest to help people sleep better, when that's there high up in their priority list. Because it might well affect their pain levels.

**Evans:** I know the consequences of diabetes can be... Well, more than awful, really. But do people prioritise what is important about their lives living with diabetes?

**Davies:** With people in pain it can be that the pain becomes the overriding thing and people become defined by their pain and often will enact strategies to avoid the pain. Because pain has evolved to be unpleasant. It's not supposed to be nice. It's evolved to protect you from damage and alert you to injuries. But in some cases it can become too sensitive, too alerting.

So if, with pain - and you may have a persistent problem that cannot easily be resolved - then living your life despite it, living your life with it, doing things that are important valued— Another speaker just this afternoon, Lance McCracken from London, gave a really good talk around how people can choose valued activities and engage in them despite how they're feeling in their body, despite the worrying thoughts that they have in their heads. If you hold that for a minute, that worry thought will be replaced by another thought quickly. Can you live a life despite it? And I think that's applicable to this neuropathic pain problem and it's probably applicable to the diabetes world as well in terms of 'You gotta live your life despite being diabetic'. I wouldn't want to make that sound as if it's a sort of death sentence.

A common thing I'd say to patients with pain is - and I'll use the diabetes analogy - you can be diabetic and you can manage it badly: eat the wrong things, drink the wrong things, be stressed - and as you've just said there can be quite a litany of consequences for that - or, the other extreme is to manage your diet really well, exercise appropriately, have a good social support system, have a clear understanding of the condition, and you will manage that condition very well and you will have very few impacts of that condition, but you'll still be diabetic. So, with pain you can think "Will I be like this forever?" and I'll say "Well, if you at one extreme sit down forever, never socialise, get more and more worried, have a really disturbed sleep structure, then life could become quite black, quite dark. If, however, you manage your stresses, exercise healthily, choose to do the things that make you *you*, have social support, have social interaction, do the relaxation exercises, whatever might be appropriate - you might still be a person in pain, but you'll be a parent, partner, lover, friend, employee, employer - you'll be a person."

**Evans:** that was physiotherapist Ben Davis. Now, I'll just remind you that whilst we at Pain Concern believe the information and opinions at *Airing Pain* are accurate and sound based on the best judgements available, you should always consult your medical professional on any matter relating to your health and wellbeing. He or she is the only person who knows your circumstances and therefore the appropriate action to take on your behalf. Don't forget that you can download all editions and transcripts of *Airing Pain* from Pain Concern's website: [painconcern.org.uk](http://painconcern.org.uk) and there you'll find information and support for those of us living with

chronic pain, our families and carers, and for health professionals. There's also information on how to order Pain Concern's magazine *Pain Matters*. All the details are on the website.

Now with in excess of twelve leg, foot or toe amputation each day due to diabetes, of which four in every five could have been prevented, I recommend you look at the Diabetes UK website: [diabetes.org.uk](http://diabetes.org.uk). Pay special attention to their 'Putting Feet First' campaign with all their advice on how to take care of your feet.

Final words of advice on this edition of Airing Pain on painful diabetic neuropathy from Ben Davis:

**Davies:** The key treatment for it is: Don't get it in the first place. Managing your diabetes effectively, preemptive management, good blood management, good diet and exercise management, - all the diabetologists I've spoken to say that's the best way to treat this pain problem. Don't get it in the first place.

### **Contributors:**

- Ben Davies, clinical specialist physiotherapist in pain management at Sirona CIC
- Linda McGlynn, Patient and NHS Engagement Manager Diabetes Scotland

### **More information:**

For more support and information on living with diabetes, as well as advice on how to look after your feet, visit:

- NHS Choices <http://www.nhs.uk/Livewell/foothealth/Pages/Diabetesandfeet.aspx>
- Diabetes UK 'Putting Feet First' <https://www.diabetes.org.uk/putting-feet-first#camp>

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\* Figures from Diabetes UK: <https://www.diabetes.org.uk/putting-feet-first>,  
<https://www.diabetes.org.uk/Professionals/Position-statements-reports/Statistics/Diabetes-prevalence-2016/>

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