

Airing Pain Programme 34: Ankylosing spondylitis, and the patient perspective

Living with ankylosing spondylitis and psoriasis, plus, listening to the patient perspective and educating health professionals.

In this programme we look at ankylosing spondylitis (AS), a form of arthritis affecting the spine. Paul Evans speaks to Iain MacDonald and Tom Downie of the Edinburgh branch of the National Ankylosing Spondylitis Society, about their role in supporting people with the condition. Paul also talks to Janice Johnson of PSALV (Psoriasis Scotland Arthritis Link Volunteers) about psoriasis.

We also interview speakers from the Annual Scientific Meeting of the British Pain Society. Pain Concern's Sue Clayton gives a patient perspective to healthcare professionals, while Emma Briggs of the British Pain Society's Pain Education Special Interest Group explains the importance of improving the pain education of healthcare professionals.

Paul Evans: Hello I'm Paul Evans and welcome to **Airing Pain**, a programme brought to you by Pain Concern, the UK charity that provides information and support for those of us who live with pain. This edition's been made possible by Pain Concern's supporters and friends. More information on our fundraising efforts is available on our Just Giving page at www.painconcern.org.uk.

Tom Downie: I went to the Ideal Home Exhibition a few years ago and the man selling the beds, he says, 'excuse me, sir, you've got ankylosing spondylitis, would you like to buy a bed'.

Janice Johnson: Some GPs are fantastic and others don't know an awful lot because their training in dermatology's been cut and some of them only get about 2 weeks dermatology training in 6 years.

Emma Briggs: We did include the vets in our survey and the vets on average did have a higher pain education in terms of the number of hours, compared to those being educated on the human healthcare side of things.

Tom Downie: I know it's nothing, but he knew just by looking at you. I mean that was just a man selling beds.

Paul Evans: More about GP training and top tips on medical diagnosis from a bed salesman later. Now ankylosing spondylitis, or AS, is a condition where some, or all of the joints of the spine fuse together. It's one of the three most common forms of inflammatory arthritis along with rheumatoid and psoriatic arthritis. They're separate conditions, but what each has in common is that the body's immune system is wrongly triggered to attack itself, causing pain, stiffness, damaged joints and, if left untreated, possible disability.

It affects around 200,000 people in the UK and I met Iain MacDonald and Tom Downie, Secretary and Treasurer of the Edinburgh branch of the National Ankylosing Spondylitis Society. Tom was a teenager when the disease took hold.

Downie: I was at boarding school and we'd be playing football or something and the next day I just couldn't move out of bed, just seized up. I just couldn't move and the nurse would come and put some Deep Heat or something on and I'd be fine a few hours later. That went on through my school years, but as I got into my 20s I'd get the Deep Heat on but it'd still be sore for 3 or 4 days and I'd be out of action for weeks, just not being able to move. I was getting all the pain killers and things and, although it would maybe take some of the pain away, you just couldn't move, you were that stiff. I never got diagnosed till I was maybe 30 years old and by then I was away stooped over, I couldn't see where I was going, life was just hell and you get depressed and things like that. Then I got my hips replaced when I was 35 and that made a big difference, constant physio and things, so now I can walk about, any distance I need a walking stick, but life's alright.

Evans: Working out the maths, it took 15 years to be diagnosed. Why was that?

Downie: At 15 or 16 at school you were seen as 'Tom you want to get off doing something, he just wants to stay in bed'. When I started working I would go to work at 18-19, you would have to have a week of here and a week off there, you just couldn't do things. And when you're that age you don't want to go to the hospital, you don't want to go to the doctors, but eventually when you do, you just get diagnosed lots of different things: its stiffness, its juvenile arthritis and I'd be in my late 20s when actually somebody says, 'I think it's this, ankylosing spondylitis', and I had a further investigation.

Evans: If you were a 15 year old now going through it would it still take 15 years?

Downie: Well I've got a son who's 22 and when he was 13 he went through the same sort of thing, he was told he had some type of juvenile arthritis and he would have days off school and things like that and he had to carry on and he, unlike me, liked school so it was quite a problem for him. With me already having it, we went to the doctor, got diagnosed fairly quick and got offered physiotherapy, so within 2 years or something he was getting offered physiotherapy, but I wasn't getting offered physiotherapy for 15 years.

Evans: So has he had a successful diagnosis because of your knowledge or has it moved on?

Downie: I think a bit of both. At first it was because of my knowledge, but the group we go to on a Monday, you do hear and you see younger people coming now, not very often, but you see them, they seem to get diagnosed in their twenties now and it would take maybe me 10 years before I had it. So they do seem to diagnose it a lot quicker.

Evans: As an organisation, the National Ankylosing Spondylitis Society, what are you doing to help people get better treatment or more information?

Iain MacDonald: Tom and myself and another colleague, Campbell Barr, have been going along to the Scottish Parliament for the last 3 or 4 years to various Committees to try and get publicity, such that ultimately the information gets spread. The members of the Society get 3 principal things: one is interface with fellow sufferers so that they get information on potential

problems and perhaps how to cure them; the hydrotherapy sessions that we're lucky enough to have in Edinburgh and gymnasium sessions. So we get an exercise regime that will help at least keep the problem at bay if not necessarily cure it.

Downie: Also, I think that if people know about the Group and they know where you can get the information, so somebody like me that got hip replacements in their thirties and I've got a son who's 22 – with him knowing about ankylosing spondylitis – because even something as simple as posture, you find out all that information, so you can avoid problems like having to get hip replacements... knowing the right physio, the right exercise, the right medication, where you can stay in work longer and things like that.

Evans: Talking about your son having it as well, is it hereditary?

Downie: Yes, I don't know the official statistics but just going by me I've got 3 sisters, one of them has got ankylosing spondylitis and another one's got psoriasis and there's a connection between psoriasis and ankylosing spondylitis. My son's got it, to see him you wouldn't notice, he looks fit, but at least with me knowing these things I can get on to him when I see him watching TV slouching, I can get on at him to sit up and it can avoid problems in your 50s and 60s. There's something that you can do now.

MacDonald: I can confirm that it is hereditary, my father had it and I have four sisters, one of whom has also got it. We're keeping our fingers crossed, I've got three kids and we have no sign of them actually having the problem yet. So, as Tom says, I'm 2 out of 5 got it so we're keeping our fingers crossed about our kids.

Evans: What advice would you have for somebody who's just been diagnosed with ankylosing spondylitis?

MacDonald: I would ask them to find a local NASS branch, and there are many throughout the country, and gain the benefits that I've personally gained from it: the speaking to people who also have the problem, finding out what their problems are and perhaps helping you getting into the hydrotherapy sessions, the gym sessions. In my personal circumstance, Campbell Barr, who I mentioned before, actually had physiotherapists organised to do measurements – there's a system called a 'Bath system' [Bath Ankylosing Spondylitis Disease Activity Index (BASDAI)] – that actually measures your degree of stiffness and pain. There's a 3 sheet set of statistics that people can measure how badly you are or otherwise. It's thanks to this measurement regime that that then got referred to the rheumatologists. I gained huge benefit personally through going along to the NASS organisation branch in Edinburgh.

Evans: Tom, on a day-to-day basis, what advice would you give somebody who's just been diagnosed with ankylosing spondylitis?

Downie: The key is keep moving. As Ian says, on the Monday night we've got half an hour in the hydrotherapy, they're trained physiotherapists, they know what they're doing. So that makes a difference, you get that hydrotherapy on the Monday, then through in the gym, 45 minutes of light stretching, you go at your own pace. And once you get into that routine of doing that, I just feel that it just sets you up for the rest of the week. Even a Jacuzzi, before you go in the Jacuzzi you might get 25 steps without a seat but once you've been in that Jacuzzi you can maybe walk 100 without a seat. Movement is the key.

Evans: Tom Downie and Iain MacDonald. And you can find more information about ankylosing spondylitis including details of the local branches of the National Ankylosing Spondylitis Society from their website, which is nass.co.uk. That's nass.co.uk.

Now, I mentioned the link between AS and psoriasis, or psoriatic arthritis. Janice Johnson helps run a small Scottish charity, PSALV. It stands for Psoriasis Scotland Arthritis Link Volunteers.

Janice Johnson: I myself have psoriatic arthritis which I've had since 1974, diagnosed in 1974, unfortunately wasn't given good treatment back in the 70s and 80s and there are now a lot of newer medications available. There's no cure, it's similar to rheumatoid arthritis in some ways in as much as it's an inflammatory arthritis but back in the 70s and for 25 years after I was diagnosed, I wasn't given anything other than non-steroidals and I should have been given second line medications. So for 25 years I had little flares and that left me with quite a lot of damage which is not reversible other than with surgery. It's similar to rheumatoid in as much as if you get in quickly with the diagnosis of this you can treat it, you can't cure it but you can treat it. Osteo's more difficult actually because it's wear and tear, but with the inflammatory types if you can get in early you can do more, so that's basically what happened to me. But I do have a lot of pain and a lot of stiffness and I can't walk very far now because I've got a lot of tendon damage – ankles, feet, knees – so my mobility's not good.

Evans: Now a lot of people might know about psoriasis but not know the link between psoriasis and arthritis.

Johnson: Psoriasis is an overgrowth of skin cells but there's also an inflammatory response and you don't have to have a lot of skin psoriasis, which is red scaly patches, to have problems with your joints. This is part of the problem, you might have just a tiny bit of skin psoriasis, just a tiny little bit and then develop sore fingers and toes which is one of the most sort of classic ones and unfortunately GPs, like a lot of things, are not terribly well trained in spotting this and the link is the inflammation, the inflammation for some reason in about 1 in 5 people with any skin psoriasis, not necessarily extensive, it doesn't have to be, you know, you don't have to be covered in psoriasis to get this, develop some problems with their joints. And again it's very rare there might be one finger and you might be in a wheelchair. So we're not trying to frighten anyone but it is a progressive thing so you do need to treat it early. Some GPs are fantastic and others don't know an awful lot because their training in dermatology's been cut and some get about 2 weeks dermatology in 6 years, which is ridiculous.

Evans: So what should people look out for?

Johnson: Well anyone with diagnosed psoriasis should be aware of this – not to frighten anyone – but if you get a swollen puffy finger or toes or actually pain in your heel – the heel's another common place – the back of your heel, sort of tendonitis, you should go and ask your doctor if you can get a referral to dermatology to see what's going on, without terrifying anyone because it might be something else. Don't get terrified and think, 'oh my God I've got psoriasis', just, you know, keep an eye on it.

Evans: I'm glad I'm speaking to you because I have a little bit of psoriasis and I will keep an eye on it.

Johnson: And you're terrified! Bear in mind most people with skin psoriasis don't get problems, as I say, it's about 1 in 5.

Evans: Well you've been rummaging through your bag and I've got exactly what I need which is a leaflet from... 'This Is Psoriasis'. I must read this and thank you very much indeed.

Johnson: Thank you very much, thank you.

Evans: Janice Johnson from PSALV, that's Psoriasis Scotland Arthritis Link Volunteers. She and the previous speakers made reference to the adequacy of training for health professionals. Sue Clayton has been involved with Pain Concern for many years. Having had chronic pain for over 30 years, she was invited to give the patient perspective to health professionals at the 2011 Annual Scientific Meeting of the British Pain Society.

Clayton: The model where someone has an acute illness they are treated and then discharged is the sort of condition governments are interested in because they get a pathway, they get an outcome that they can measure. Chronic pain's a very different sort of condition, it's a long-term condition, people have probably got it for the rest of their lives, unfortunately, and I think it calls for a different sort of relationship with the clinicians the patient is working with, in a way a much more caring relationship, and I think one of the hardest things that patients like me are facing at the moment is the way that medical services are changing – it's that patients like me desperately need continuity of care with their medical advisers and that is what is being lost in the health service at the moment.

It doesn't make sense for me to have to go into my general practitioners and be prepared to see anybody of the 5 GPs who work there and have to repeat my story endlessly so that they understand where I'm coming from. They have doubts usually because of some of the drugs which I'm on, whether this is suitable, whereas my much lamented, splendid GP who's recently retired, because she'd known me for 20 years, we'd built up a relationship and she trusted me. I trusted her to give me the best available care that she could manage but she also trusted me, she knew that I didn't swing the lead, she knew that I took my drugs responsibly, she knew that I put effort into self-management, she knew that if I came to her and said 'things have got much worse. I help need with a particularly difficult period, a bad flare-up...' that that was genuine, I wasn't making it up. And she only knew that, because she'd known me for a long time and you know, known me over a period of time. And that's being lost and that makes it very difficult for GPs at the coal face to work with people with long-term conditions like chronic pain because they're complex, pain is subjective, it's invisible. In a sense they have to take an awful lot on trust of what their patients are saying and how can they have that trust if they haven't built up a relationship with the knowledge of their patients. So at the moment it's very, very difficult I think.

There needs to be a huge amount more training going into clinicians dealing with chronic pain, both right from the undergraduate level, right up to specialists... to understand that patients really struggle to cope with their lives and that a lot of them are really doing their best, but that often life is extremely difficult and also pain fluctuates so much, you may go along fine for 6 months and then wake up and for some unknown reason, you have a terrible flare-up, that's what happened to me 3 weeks ago, nothing I could put my hand on. People say to me all the time, 'oh do you know what happened?' And I say 'no.' And that makes it

very difficult for the patient because they don't know what to avoid, they don't know how to manage better.

If there was a trigger, I know that if I do something really stupid, if I dig the garden, of course I'll have back pain but it can happen without any warning at all. And this makes it so difficult to explain to clinicians and for them to believe you, because perhaps they've seen you out and about and you look perfectly alright. I mean most people seeing me would think I look perfectly normal, they don't know that sitting here today I've got searing, burning pain from my waist to my toes – it just isn't visible.

How do you judge somebody like that, it's a very difficult situation both for doctors and for patients and so I think there really has to be a model where patients have continuity of care, in a relationship where they trust the doctors to actually believe what they say, they accept it and be prepared to perhaps put the barriers down a little bit, treat them as human beings who are capable adults who are trying to lead their lives as well as possible. Nobody wants to be in this situation; they've had it forced upon them. I would give anything not to be living like this but I have to. It's very easy to judge people with chronic pain and judge them very unkindly and that happens with both the general public and from clinicians and other health professionals at times... to take things on face value without actually talking to patients and finding out what's going on underneath.

Evans: Sue Clayton, who spoke at the 2011 British Pain Society Annual Scientific Meeting. In the following year's meeting I spoke to Emma Briggs, she teaches at the Florence Nightingale School of Nursing and Midwifery at Kings College London. She's also Chair of the British Pain Society's Pain Education Special Interest Group. Their aim is to enhance the education of qualified health professionals and the patient education that they provide. So why should healthcare professionals who've been through years of training need this?

Emma Briggs: Very good question. We recently conducted a survey that we published within the European Journal of Pain which looked at the amount of education that was provided to our undergraduates and that looked at the education that was given to dentists, to nurses, doctors, midwives, physiotherapists and pharmacists and the number of hours of education that they receive is actually very low: the average hours for a midwife was 6 hours, in the whole of their curriculum; nurses receive an average of 10 hours; doctors an average of 13 and the overall average was 12 hours of education.

Evans: And you're talking about education, about pain issues?

Briggs: About pain, yes and considering it's the reason that people seek health care and the amount of pain that people experience that's a relatively low number in their curriculum. So it's less than 1% of their curriculum that actually includes pain management, so we are trying to increase the number of hours of education devoted to pain management but also how it's taught within our universities within the UK.

Evans: You missed that one category in your list and that's vets.

Briggs: Vets – yes, now we did include the vets within our survey and we replicated this survey from Canada and there were five vet schools within the UK and unfortunately we only got two respondents. But the vets on average did have a higher number of pain education in terms of the number of hours compared to those being educated on the human healthcare

side of things. However, we can't, you know, it was only two schools. But it is a surprising statistic that they have a higher number of hours in their curriculum, but that comes down from their regulators. The regulators of the veterinary undergraduate programmes stipulate that pain should be in there and then the quality assurance body that follows that up to make sure that education is being delivered well – they say that pain should be in there so they kind of attack it from both sides, whereas, as part of the survey we looked at the healthcare regulators, such as the Nursing and Midwifery Council, the General Medicine Council, whether they had made those stipulations – and in some cases they had but in many cases they hadn't, you know, so we really need to tackle things from the Regulator so that they encourage and stipulate that pain should be in the curriculum.

Evans: It's hotly rumoured that there's an event this summer called the Olympics.

Briggs: Yes.

Evans: You've managed to get it into one of your titles as well.

Briggs: We have indeed and our workshop today was called Citius Altius Fortius and launching our Olympic campaign for pain education. And that was really about saying, there's been some great developments about pain education for healthcare professionals for patients and the public, but actually we need more and we need to be higher, faster and stronger on this and we really need to push the agenda you know, and one of my lines within the workshop was, 'you haven't got a £2 billion development fund neither have we got a one-eyed mascot', but there's much that we can do collectively to really move this agenda forward. And we've been working with a number of people and from that workshop some great ideas have come out and we will be sort of rolling those out to kind of improve pain education over the coming months.

Evans: What sort of ideas?

Briggs: Well we have the inter-professional undergraduate curriculum document coming out later on in the year, so that's a working party that's being chaired by Dr Nick Allcock and we are looking at producing a document which really helps people put pain education into their curriculum. Because people can face a number of barriers one fellow academic said to me 'but my Head of Department has said, I've got a number of penguins on my iceberg which one do you want me to push off in order to fit pain in the curriculum?'

But we want to change these sorts of attitudes to say, you know we don't need to push off any penguins, we need to make sure that each penguin knows how to manage pain but you know they've got the skills to do that. So this document is a real sort of practical... how to help the person champion pain management within their university, how do you integrate it, how do you try and get healthcare professionals learning and working together, because the reality is in clinical practice that nurses, pharmacists, doctors all need to work together to help the patient, but at the moment our survey has shown that they don't; they don't learn together, they learn separately on their courses and we need to change that. So this document is very much about saying how can you get the healthcare professionals learning with, about and from each other, so that when they qualify they are able to work really well inter-professionally and for the best interests of the patient really.

Evans: Tom, do you find that doctors find difficulty in diagnosing your condition?

Downie: Well years ago, yes, but younger medical students, younger doctors, they can look at you and some of them see you walking into the room and they think, 'ankylosing spondylitis', you know. I went to the Ideal Home Exhibition a few years ago and the man selling the beds, he says, 'excuse me, sir, you've got ankylosing spondylitis, would you like to buy a bed?' You know what I mean?!

So, I know it's nothing, but you know what I'm saying – he knew just by looking at you, and that was just a man selling beds. And I think as well, the younger students, they can see, but that can be a danger as well because somebody like Iain, although his neck's stiffer and that, he's not stooped over like me. But just because you're not stooped over you can still have ankylosing spondylitis.

Evans: But you were telling me earlier that you get involved in training doctors and even consultants.

Downie: Well yeah, it's just called 'Exemplar Patient Programme' and its 3rd and 4th year medical students and we spent an hour-an hour and a half in the room with them talking to you, and they want to know how you were first diagnosed and how you feel your GP in particular dealt with your problem and how you feel it could be improved and if they become a doctor in 5 years' time and somebody walks in with a sore back, how could it be improved.

Evans: So in short, you go along to the hospital as an exemplar patient; a group of doctors, young and old, come in and they have to work out what's wrong with you.

Downie: Well yeah, as I said, you go down there, there's maybe four or five other people like me and we get put into five rooms and there'll be four or five groups of students and their job is to try and guess what's wrong with that person. And there'll be me with ankylosing spondylitis, somebody with rheumatoid arthritis, somebody with other forms. And I have noticed over the years of doing this, they seem more informed than the doctors were 20 years ago, put it that way.

Evans: So, of the consultants, the student doctors and the double bed salesmen, who gets the best training?

Downie: [Laughs] I think the young doctors, the 4th year students seem to be more with it now than ever before, in my opinion anyway.

Evans: The big thing about pain education is that all the information and the help is there but we just don't know it's there.

Briggs: Yes, yeah. It's very true actually. Dorothy Helme here is our link with the Patient Liaison Committee and is a co-opted member of the Education SIG [Special Interest Group] and she was reflecting on that point this morning when she was telling her journey from when she first started experiencing pain to her diagnosis. She was saying, you know, 'I am a nurse by background, but I am a pain sufferer and I did not know where to look and there was not nearly enough information out there for me, couldn't find the information, I hadn't even found the information from the British Pain Society'.

So again there's a lot to be done there in terms of awareness and helping people find the appropriate and well-informed information resources for them; and support groups and specialist support groups as well.

Evans: Emma Briggs, Chair of the British Pain Society's Pain Education Special Interest Group.

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Briggs: The internet is a fantastic resource but it can also contain some very unreliable information; and in fact Dorothy was reflecting on her experiences of using the internet and finding very negative information on the internet, which was not helpful for her as she was searching for some help for her facial pain condition. And it's very difficult to judge, I mean, the students that I work with they have a whole programme on how to use the internet effectively to actually make those judgements as to who is it written by, when was it last updated, what was the purpose, was there any advertising around with it that might be influencing it. It's very, very hard to actually judge whether this is a reliable source of information and actually whether the person who's written it is actually a real doctor, nurse etc. So it is a difficult judgement to make, and of course you type your key terms into some internet searches and you may get sites which actually have paid to be top of the agenda and so therefore they might have some certain biases as well.

Contributors

- Tom Downie, Treasurer of the Edinburgh branch of the National Ankylosing Spondylitis Society
- Iain MacDonald, Secretary of the Edinburgh branch of the National Ankylosing Spondylitis Society
- Janice Johnson, PSALV (Psoriasis Scotland Arthritis Link Volunteers)
- Sue Clayton, Pain Concern
- Emma Briggs, Lecturer, Florence Nightingale School of Nursing and Midwifery at Kings College London and Chair of the British Pain Society's Pain Education Special Interest Group

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