

Airing Pain Programme 83: Arthritis: from self-help to cutting edge research

Getting moving with tai chi, staying in work and why arthritis pain is not all about the joints.

Over ten million people in the UK live with arthritis and it is the most common cause of pain. Professor David Walsh of Arthritis Research UK explains what causes the different types of arthritis, why the nervous system is the main culprit in arthritis pain and he updates us on the most promising lines of current research into drug treatments.

But there is much more to living well with arthritis than taking medication as Producer Paul Evans finds out at an Arthritis Care Wellbeing Day in Renton, Scotland. He joins a specially adapted tai chi lesson and finds out from Sharon MacPherson about what to eat and drink and what to avoid when managing the condition: ‘Sassy Water’ is in, alcohol is out.

The workplace can be a challenge for anyone managing pain with 50 per cent of those with rheumatoid arthritis leaving work within a year. Hazel Muir explains the importance of knowing your rights and being able to explain about your pain to employers and colleagues.

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 is funded by the Agnes Hunter Trust.

[Background conversation]

Loudspeaker announcement: Good morning ladies and gentlemen. Just a wee reminder that our wellbeing day is going on downstairs in the lounge, if you’d like to join us.

Sharon MacPherson: Hi everyone. What I’m going to do today is just do a wee demonstration and maybe get you to do a bit of the warm up of the tai chi. So, I’m just going to start off by showing you the salute that we do at the beginning and the end of the class. So if everyone takes their left hand, and put your four fingers together, this signifies

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friendship and when you put your thumb in like that's humility. So you then get your right hand and you make a fist, and then you put the two together like this and that's your salute. So at the beginning and the end of the session we always do that and it's a sign of mutual respect.

Evans: Now, according to Arthritis Care UK, Arthritis is the biggest cause of pain and physical disability in the UK. Around ten million people live with the condition. And according to a survey carried out by Arthritis Research UK with the Daily Telegraph, three quarters of those living with arthritis and joint pain say the pain stops them living life to the full. That's why I've come along to Waterside View Residential Home in Renton in Scotland, where residents are taking part in a wellbeing day. But, before we join them – what is arthritis? David Walsh is Professor of Rheumatology at the University of Nottingham, and he's Director of the Arthritis Research UK Pain Centre.

David Walsh: The commonest form of arthritis is osteoarthritis. It's something which increases with age. People sometimes call it 'wear and tear' arthritis, although I tend to think of it as an ongoing repair process that's going on in the joints. Less common than that – a major problem for those that have it – is the inflammatory forms of arthritis, things like rheumatoid arthritis, psoriatic arthritis. Those are characterised by the body's reaction against itself if you like, which is damaging the joints. They often come on much earlier in life. But sadly for none of these forms of arthritis do we have cures.

And then there's another group of conditions called crystal arthritis, for example, gout, which we have good treatments to control, but again not everybody gets on with those treatments and there are still problems with those. They are typically characterised by intermittent episodes of pain.

And then there is another very big group of people who are experiencing musculoskeletal pain for which there's no clear immediate drive coming from the joints or the muscles. And there's a condition that people often refer to as 'fibromyalgia', where despite intensive research it's been difficult to pinpoint exactly what's going on in the periphery in the joints and the muscles and it seems the main changes are going on within the nervous system.

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MacPherson: My name is Sharon MacPherson. I work for the charity Arthritis Care and I'm the Project Officer for Joint Activity, which involves various activities including tai chi for arthritis and health walking. So I support the volunteers. All our services are delivered by volunteers, so I'm there to help them deliver the service.

Evans: So tell me where we are and what we're doing?

MacPherson: Today we are in Renton and this is a Wellbeing Day and I'm here to support my colleague Hazel, who works with the Working Well with Arthritis Programme. And within my work they have helped me with a referral to Access to Work, which helps me stay in work with arthritis.

Evans: So you have arthritis?

MacPherson: I do, I have an inflammatory arthritis called rheumatoid arthritis.

Evans: And how does that affect you?

MacPherson: Generally it affects your whole body, and there's an element of fatigue with it, and pain, that's the two main features. But because I work for the organisation and I look after myself it's fairly well managed.

Evans: So how do you manage it?

MacPherson: Various things. Activity is one of the main things. I need to keep moving or I stiffen up, so I walk with the volunteers, 'cause we do the Health Walking project, and I'm trained to deliver tai chi, so I do tai chi every day as well. And it's tai chi for arthritis so it's a nice high stance, there's no big expansive movements so it's easy on your joints.

So we recruit the volunteers, we train the volunteers and then I support them to go out into the community and deliver the services. We also have self-management volunteers that I support and they deliver self management workshops which have different topics and one of them being understanding pain, which is a main feature of arthritis and the conditions.

Evans: Understanding pain, that might confuse many people because you don't need to understand pain you just feel pain, it hurts.

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MacPherson: Well, it does hurt, but you do need to understand it to help yourself because if you can understand it you can manage it better.

Walsh: A lot of the pain in people with active rheumatoid arthritis is being driven by inflammation of the joints, and when the joint is inflamed it's producing chemicals which are not only setting up that inflammatory response, they are also making the nerves sensitive to movement and pressure and so on. So if you can in those situations damp down the inflammation, you can substantially relieve the pain. The difficulty we have in rheumatoid arthritis is that actually once you've suppressed all that inflammation people often still have significant, important pain. And the mechanisms of that ongoing pain after the inflammation has been settled is much less clear and, again, seems to be more related to the way that the nervous system is working, rather than any residual inflammation or damage in the joint.

So, if the joint is damaged or inflamed then it sends signals to your brain to tell you that something's going on. Of course, your joints are sending signals all the time, so even if you don't have any pain, if you're walking, your brain knows where your leg is – called proprioception, joint position sense. And part of what can happen is that the nervous system can start switching those signals, those normal experiences in the joints, into the pain pathways, so instead of feeling something as being pressure, or as movement, you feel it as pain. So it's not just that the nerves are being irritated or sensitised in the joints, but actually the whole network through which those signals are getting to the brain can change.

Evans: How do you treat the nervous system side of that then, rather than just inflammation?

Walsh: There are treatments which are targeting the nervous system, the oldest one is probably opiates, they actually block pain signalling within the nervous system. But treatments which may have been developed for other purposes, depression or epilepsy, because of the way in which the nervous system uses common signalling pathways in a

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number of different areas, some of those drugs can be helpful for pain. So drugs like amitriptyline, duloxetine, gabapentin, pregabalin, have been repurposed for 'nerve mediated pain', if you like.

Obviously there are other ways of changing the way the nervous system works, psychological treatments actually primarily work through the nervous system, they aren't working on the joint itself. And there's quite a lot of evidence that it's not just what you think you feel, but actually psychological treatments do change what you feel, it is real. So I don't think we're necessarily just talking about drugs in terms of the way the nervous system processes things.

Hazel Muir: My name's Hazel Muir, I'm an employability officer with Arthritis Care, specifically with the Working Well with Arthritis Joint Working Service. We're here today, we've been asked along today to provide some information on some of the services that we provide throughout Scotland.

Evans: Well a lot of the services I can see laid out on your stall, your table in front of you at this wellbeing event. Explain to me, I can see coping with pain there, now pain and arthritis, tell me if I'm wrong, they go hand in hand?

Muir: Oh yeah you're definitely right, and I would say that's one of our most popular leaflets. We've got a lot of useful information on there, some hints and tips on some of the things that you can do to cope with pain and pain management. We've brought a sort of selection of some of the information leaflets that we provide. I've also got just a few things on living with osteoarthritis, living with rheumatoid arthritis, exercise and arthritis, and healthy eating.

Evans: Sharon it's coffee break, you are holding a flask of something that looks absolutely disgusting to me [laughter], what is it?

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MacPherson: Well I call it 'sassy water'. It's not disgusting, it's actually quite pleasant to drink, but it's just water with cucumber, ginger and lemon and it's an anti-inflammatory water, so it helps with my arthritis. I actually gave the recipe to my neighbour, he has gout and he's never been able to control his gout, and I gave him this recipe and he went on holiday for five days and didn't drink the water for five days and his gout came back. As soon as he came back and he got back on the sassy water and his gout's away.

Evans: So how important is diet?

MacPherson: Diet's really important with arthritis, because it's an inflammatory condition, there's lots of food you can eat to help your condition. The girls in the centre here brought us beetroot juice earlier, that's another thing that's really good for your joints and your bones.

Evans: It was lovely.

MacPherson: It was nice, it was very pleasant, it is nice. So I sometimes put that in. I've got a juicer at home, that juices the juice out of everything, it's a cold press juicer so it's really good.

Evans: So what should people with arthritis avoid, are there no-no foods?

MacPherson: Well it's about finding what works for you. And we do have information leaflets available that will guide you with diet and drink. But there's obviously things that are inflammatory. Alcohol is inflammatory so you should avoid that. But there's lots of good foods, pineapple has got something in it called bromelain and it's really good, it's an anti-inflammatory so pressed pineapple juice is good as well. It's high in sugar so you just need to watch your intake is not too high.

Real foods are always good, so when you think of real foods it's something that's grown from the ground, so natural foods and fresh foods. Usually the bright colours are full of antioxidants – so lots of vegetables and some fruit.

Evans: Well it's getting busier and busier and we're stopping people getting at your stall. Let's go somewhere just a little bit quieter.

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Let's go back to your 'Coping with Pain' leaflet. Many people might think that coping with pain means drugs from the doctor.

Muir: That's certainly one thing. Obviously we promote self-management, we include a number of things that you can do in the way that you're taking control of your own condition and how you want to maintain and manage that condition.

Evans: There are lots of changes, not just to the person with arthritis, work, office situations, family, **[Muir: Yes.]** siblings, parents.

Muir: Absolutely, a huge support network sometimes. Communication is key there. Often it's about getting across how you're feeling and what's going on with you to the other people around you. You mentioned employers and colleagues and so on, Working Well with Arthritis Joint Working Service that I actually work with, that started in 2014. And it kind of came off the back of a lot of research that we had in the UK about the challenges people were facing that had arthritis, when they were in the workplace or trying to return to work.

Evans: What are those challenges then?

Muir: There was a piece of research done in 2010 by the National Rheumatoid Arthritis Society. And there's some really good information that came out of that. That's kind of key to what we took on board when we were developing this service. And one of the pieces of information from the participants that took part was that within one year of people being diagnosed with rheumatoid arthritis over 50% of them had left work; within a six year period 80% had left work.

Evans: That's astonishing.

Muir: It is quite staggering figures. And some of the other things from that same piece of research people with rheumatoid arthritis had identified a number of areas as the most important factors that would help them remain in work and from that we introduced this service.

Currently, at the moment the service is delivered in Glasgow and Greater Clyde and also in Grampian and we work very closely with the NHS in both areas, hopefully with the aim to

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complement the service from the NHS. But some of these areas that we talked about from the report as what was most important to the person with arthritis was a better awareness of their own rights at work, to have increased knowledge and flexibility from their employer and better awareness of schemes to assist people in work. These are fundamental to the service that we've developed to address some of these areas.

Evans: In many ways you say being aware of one's rights at work, there is a danger there isn't there, that that sounds confrontational, you're table thumping, 'I want my rights'. The ideal situation is that you wouldn't need those rights written down, that employers and employees would be able to work together, how do you get around that?

Muir: Well I think the main thing is that people that get in touch with us for the Working Well with Arthritis, quite a number of people are not aware that there is protection from the law, mainly the Equality Act 2010. And I think that's a big key thing, because a lot of the concerns from themselves is around their absences and what's going to happen when they go back to work, is there going to be issues around discipline and so on. And that's quite common that we see through the people we work with.

So getting across this is what the law states and this is what's there to protect you and it's ok to expect certain things and to have that conversation with your employer and that they have a duty of care as well. And really just getting that across in a way where the individual doesn't feel like it's too much or they're being treated differently or specially, they're entitled to it. That's a key thing that we try and get across and that was one of the areas that came up from pieces of research saying that's what people wanted to know. What are the things that are there to help protect them and to allow them to continue in work?

Evans: One of the issues I guess as well for people with arthritis, as with many chronic pain conditions, is that many people don't look unwell, they don't look as if they're in pain.

Muir: Again that's a common thing, people often say that 'if I was wearing a bandage, if I had a plaster on, then people maybe wouldn't look at me the same way, or ask me the same questions'.

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Again arthritis, if you look at rheumatoid arthritis and various other fluctuating conditions, one day will be totally different from the next and, again, that's something where we hear people say their colleagues don't always understand it, or their employer, because 'you managed to do that yesterday, so how can you not do it today'. That's back to the individual understanding their condition and how that affects them, and maybe then having a look at who else needs to know that, and how do I share that information, so that they're aware and they can understand that 'I may not look in pain, but I'm dealing with pain'.

And the other thing is, pain is a big part of it, but there is other aspects to look at. Fatigue is one that we commonly get, people saying the fatigue is a real struggle, a real challenge when you're working and to get other people to understand that fatigue is not, 'I just feel tired because I never slept properly last night', there's a lot more to it. And then there's other things that come off the back of that, so people that are coping with pain each day they've got so many challenges and changes in their life and that can affect people's mental health as well. So there's things like anxiety and depression and all that can go into it. So the whole load of stuff around that, and coping with pain is a massive challenge, but it's part of it, so it's looking at addressing the other issues as well.

Evans: Another thing, another aspect of that is also, I suppose, that people in those situations where you cannot see the pain, they will work doubly hard to prove themselves, or to prove to their colleagues that they can cope.

Muir: Absolutely, yes, that's a common one. And speaking with someone recently who said that, they were basically battling themselves, because as much as they knew this was going on, they felt they were letting themselves down and letting other people down, so they were actually making them self worse by doing more than they should have and not pacing. And pacing is a massive thing here, which helps you self-manage your condition. That's another thing that people have to get to that point when their accepting of, this is my condition this is how it's going to affect me.

But there is things, it doesn't mean that my life is over and that I have to totally change everything, there's things that I can do and I maybe have to look at doing things I did in a different way, or changing from that particular route to another route. Once people accept that and realise that they can live well with arthritis, they can work well with arthritis, they

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may have to work at it and you will probably need more support, but there is support and resources out there.

Evans: So we've come outside on a grey Scottish day, there's a term Scots use for it, the Welsh term is 'miserable'.

MacPherson: It's a bit dreich.

Evans: 'Dreich', that's the word I was thinking of. So right, I'm newly diagnosed with arthritis because the doctor says I'm a certain age and that's what's expected.

MacPherson: So, would I be right in saying that you've been diagnosed with osteoarthritis?

Evans: He said osteoarthritis.

MacPherson: So, general wear and tear. That is fairly common as you get older and sometimes if you've done sports you can be susceptible to that. It's the most common condition and then rheumatoid arthritis after that, they're the biggest numbers.

Tai chi for arthritis would be fine for you, you would enjoy it, and it would be ok for your knee
Shall I give you a wee demonstration?

Evans: Yes, please.

MacPherson: Ok.

Evans: So you're standing with your feet slightly apart, shoulders dropped yeah?

MacPherson: Yup, nice and relaxed, and you want to just move your weight from the right to the left and then get yourself centred so you feel as if you're rooted to the ground. So you're

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nice and solid on the ground. Your knees want to be loose, you don't want your knees to be locked. Just feel you're weight going straight down through both your feet.

Evans: So I'm just rocking side to side, back and forth, just...

MacPherson: Just to get your balance and to get your central point and I'll need you to stand back a bit.

Walsh: I tend to think of osteoarthritis and back pain as being an ongoing repair process rather than wear and tear, I don't see it as an aging problem. It's inevitably true that anything that we don't have a cure for will get more prevalent the older you get, because you collect things as you go through life. I collect scars on my skin as I go through life, but I don't see the scars on my skin as being a disease, or necessarily a problem.

The problem with osteoarthritis is the pain, the stiffness, and the disability that it causes. And that isn't necessarily something that increases with age, even though what you see on the x-rays will change, will increase with age. We're struggling at the moment I think to identify what is the difference between normal ageing and a disease called osteoarthritis. And my feeling is that that's probably meaningless, that actually we all have changes in osteoarthritis as we get older, if you look at people's x-rays or you look in the joints with an arthroscope you'll see furring of the cartilage or some loss of the cartilage, all these things that we recognise as being part of osteoarthritis.

But it doesn't necessarily cause you a problem and really the clinical problem of osteoarthritis is more about pain, rather than about what you see on an x-ray. And there have been advances in what are the imaging or biochemical correlates of that pain. So although we've often thought of osteoarthritis as being non-inflammatory actually there is inflammation in the lining of the joint which is associated with the pain that people experience in osteoarthritis, or at least some of those people. There are changes underneath the cartilage, underneath the cushioning of the joints, changes in bone turnover, which are associated with pain.

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And actually that's leading to new types of treatment. Hitting those changes in structure and function in the joints which are causing the pain, which are beginning to show good promise as treatments to relieve pain and to prevent the progression of pain in osteoarthritis.

MacPherson: You open and close your hands and if you breathe in and then breathe out.

Evans: And I close my eyes to get the best benefit of good breathing exercises.

MacPherson: Yes that's when you close your eyes, because in tai chi if you can't actually do the movement because of pain you can visualise the movement. And they've done studies that the visualisation of the movement is almost as good as doing the actual movement.

Evans: I have to say I have fibromyalgia as well and I did a course in tai chi, and I had to give it up because it was hurting me too much [**MacPherson:** Ok.]. It was very, very hard on the knees in fact, and the warm up exercises were actually causing me a lot of problems [**MacPherson:** Ok]. So there are different types of tai chi?

MacPherson: Yes, there's over two hundred different types, there's lots and lots of different ones. The one we do was designed by doctor Paul Lam – he's a doctor from Australia – and he designed Tai Chi for Health, which incorporates all different health issues and arthritis is one of them. So it comes from the Sun Style and it's a very high stance, non expansive movements and it's specifically for people with arthritis. And there's nothing that's too strenuous on your knees.

Evans: That's right, it's just gentle moving [**MacPherson:** Yeah] and balance as you say.

MacPherson: Yeah, and there's a lot of qigong in the tai chi for arthritis, which is like a healing therapy, and it's connected with your breath.

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Evans: What I remember about qigong is I seem to remember putting my hands above my head and moving round as I breathe in from my diaphragm [**MacPherson:** Yes], I'm sure there's more to it than that, but it is incredibly relaxing.

MacPherson: *Chi* means your energy. And your chi point is three fingers below your tummy button and three fingers in the way, so that's where your chi centre is. So that's where all your energy comes from, so you're wanting to work it from there all the time. And *gong* means work, so it's like energy work, so you're working your energy.

Evans: I gave the clue away that I'm nearly sixty and my doctor says, 'well, that will be osteoarthritis'. How practical is it for people to go to tai chi classes?

MacPherson: So long as they're appropriate tai chi classes, the tai chi for arthritis would be fine because of the style that it is. It's for people with arthritis so it's nice and gentle.

Evans: But be careful which form of tai chi you chose?

MacPherson: Yeah, be careful which form. It needs to be gentle and it needs to be appropriate for your condition.

Evans: I have to say that having been put off by an inappropriate tai chi method [**MacPherson:** yeah] and feeling this one today, I'd very much like to go along to another class.

MacPherson: And you could try seated first of all, to build up the muscles around your knee 'cause it will take time to do that. And just kinda go easy on yourself, don't be too hard on yourself, because it takes time.

Evans: No pain no gain, doesn't count with arthritis,

MacPherson: No, no don't use that adage, just take care. Self care, look after yourself. Pitching it at the right level, pacing it so that you're not doing it too much.

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Evans: What's over the horizon if you like, or just visible over the horizon for arthritis pain research?

Walsh: In terms of new drugs, the most impressive thing that I've seen being developed over the last few years are drugs targeting the growth factor. So nerve growth factor is produced by the joints during inflammation. It's also actually produced by other parts of the joints as well, but think of it as being produced by joints in inflammation. And it's one of the main drivers to the nerve endings in the joints becoming sensitive. So you can imagine that if you block that then they should be less sensitive, you should be able to do more without it being painful.

So there's a number of drug companies which have developed antibodies which block nerve growth factor. And they are consistently showing very impressive improvements in pain in people with osteoarthritis, or people with back pain. It's very difficult to find drugs that work in back pain so this is really quite impressive. As with all drug developments there may be concerns about possible side effects, and these are in early stage of development. But I would see these things coming through in the next few years.

We already have a lot of treatments that show some effect in some people for arthritis pain and one of the challenges I think we have is bringing them together so that people can get the best out of what's already there. At the moment typically what happens is that you go to your doctor where you try one thing, it doesn't work so you try something else, doesn't work you try something else. And, actually, each time your treatment fails the more challenging it is to get benefit from another treatment.

And if we could target treatments to those people at the right time, when they're most likely to benefit from them, it could reduce a lot of suffering already with existing treatments. And I think understanding how we can work out who is most likely to respond to which treatment is one of those areas which is moving very quickly at the moment.

Evans: That was Professor David Walsh, director of the Arthritis Research UK Pain Centre. Their website is arthritisresearchuk.org.

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I'll just remind you that whilst we in Pain Concern believe the information and opinions on **Airing Pain** are accurate and sound based on the best judgements available, you should always consult your health professional on any matter relating to your health and wellbeing. He or she is the only person who knows you, 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, which is painconcern.org.uk. And you can find out more about living well with arthritis at arthritiscare.org.uk.

I'll leave you to finish off the tai chi session with residents of Waterside View Residential Home in Scotland.

MacPherson: Turn your palms towards you, bring your energy towards you. Breathing out, going back the way, tucking your chin in against your chest, nice and slow. And then you want to breathe in again to come back up.

Do you feel any different after you've done it? Sometimes you feel relaxed after you've done it. Thank you everyone, well done. [applause].

Contributors

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