

Airing Pain Programme 27: Arthritis – Challenging Perceptions

Setting the record straight on arthritis, and practical tips on living with the condition.

In this programme we tackle the issue, raised by Judy on our forum, of how people with arthritis – which often has no obvious physical symptoms – can get help in explaining their condition to those around them. Professor David Walsh explains about the different kinds of arthritis. Jo Cumming, Kate Llewellyn and Minal Smith of Arthritis Care talk about their own experiences of the challenges of living with pain and how the information the charity provides can help people like them.

Although arthritis is commonly thought to be a condition which only affects the elderly it can affect people of all ages – even babies. Kate Llewellyn, who developed arthritis at a young age, tells us about Arthritis Care’s booklet for parents, which provides strategies on how to adapt family life when a child is diagnosed with a form of the disease.

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 is made possible by Pain Concern’s supporters and friends. More information on fundraising efforts is available on our Just Giving page at painconcern.org.uk.

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Lexi Barber: ‘Oh you are looking better’ is one of the worst things someone can say. They mean it is a compliment but, actually, it’s like ‘I might look fine, but I *really* hurt right about now.’

Kate Llewellyn: ‘Oh, you are too young to have arthritis’ and you spend your life going, ‘Well, actually no I am not’. Babies can be diagnosed with arthritis. It can happen at any age to anybody.

Evans: In today’s edition of **Airing Pain**, we are coming to grips with a question by Judy on Pain Concern’s message board. It relates to the 10 million or so people in the UK who have arthritis and of course their families, each affected in a unique way. This is what she says:

'My husband has arthritis and has recently suffered a very bad flare up. I think one of the issues for people with pain is the lack of understanding in those around them of what they are going through. I know that in my husband's case, he has the "just need to get on with it" attitude, which can often be misread. So they also have to take on the burden of educating those around them, of what living with pain is like and how they may provide a better supporting role. What resources are there to help people in this situation?'

Well, Judy, today we are looking at one such resource provided by the charity Arthritis Care, but before that we need to know what arthritis is. David Walsh is Associate Professor in Rheumatology at the University of Nottingham and he is Director of the Arthritis Research UK Pain Centre.

Professor David Walsh: 'Arthritis' is an overriding term used to describe a whole series of conditions that affect the joints, ranging from what is the commonest form of arthritis, osteoarthritis – which I tend to think of as a repair response in the joints – through to conditions such as rheumatoid arthritis, which are inflammatory conditions, which erode and damage the joints. Osteoarthritis probably affects everybody at some stage in their life. Conditions such as rheumatoid arthritis are much less common, but are very important, because they cause a lot of problems, maybe, two per cent of the population in the UK, may have rheumatoid arthritis. There are some other forms of arthritis which are much rarer than that. One of the factors that is common across all forms of arthritis is that they cause pain.

Cumming: My pain is always there, it is like a subtext going on.

Evans: This is Jo Cumming of Arthritis Care.

Cumming: My ankle is reminding me now, it is like a low level deep pain but it is not bothering me because I am used to it and I guess for me, that's normal. However, at times, it feels like somebody has got a red hot needle and they are just poking away in that joint. You are wincing as I am telling you this.

Evans: I am.

Cumming: I am sure there are a lot of people who identify with this, then it turns into maybe a nail file that is grinding on the bone and that is a bit horrible. With arthritis, especially, sometimes, that sharp pain is accompanied by the noise of bone grating on the bone [laughs], which is horrible, and when you hear it – it is not so much the pain – it just makes you feel sick –

'Ooh! There is a lot of damage going on there!' [laughs] It is such a visceral reminder that things are not right.

Evans: Well, I am glad you can laugh about it. But you talk about a low level pain...

Cumming: Yeah.

Evans: I know what a low level pain is – that is fine today, I can cope with that today. You can probably cope with it today.

Cumming: Yeah.

Evans: but it's there tonight, it's there tomorrow, it's there tomorrow night....

Cumming: Yes, and it stops you sleeping, it affects the whole quality of life. When arthritis flares up, especially for the inflammatory forms of arthritis, it is excruciating. You do not sleep, it hurts to move and yet, we tell people all the time – 'exercise is great' – and they say 'Yeah, but it really hurts'.

Walsh: How people understand their pain has an important impact on how they manage it. If, for example, you understand that the pain in your knee is a sign that your knee is being damaged by whatever it is that you are doing then, you will stop doing it. Now, it could be that in fact, what you are doing is the best thing in the long term and therefore, if you stop doing it, actually, you will do worse in the long term.

In other words, sometimes what we believe about what is going on, can inhibit us, can prevent us from pursuing a treatment. For example, if you twist your ankle, it hurts to walk on it and the instinctive understanding of that is 'if it hurts when I am walking on it, I must be doing more damage and, therefore, I should stop walking on it'.

And yet, we know that if you don't walk on a twisted ankle until the pain has completely gone away, then you will end up with a weak ankle. You lose the protective reflexes and then you are more likely to go over on it again, you are more likely to get a twisted ankle again. So in fact, what we tend to advise is that, as soon as people can, they should take the painkillers, but they should try and walk as normally as possible on the ankle so that it repairs in a way that it actually does the thing that they want it to in the long term, which is in some ways counterintuitive.

The same thing applies to, for example, osteoarthritis of the knee. People stop walking because they have got pain in their knee, then in the short term the pain may feel better but, in the long term, as they lose the muscle strength round the knee and again the protective reflexes, they may become more disabled. And, in fact, one of the cornerstones of advice for osteoarthritis with the knee is exercise. It is about keeping the muscle strong. It is about maintaining your activities.

Cumming: Some days I do not want to go on an exercise bike, but I know that if I do, and do it slowly and work through it, it will improve the quality of my pain and help me cope. In fact, now, because I have been really quite good at doing this, it has helped me lose weight, I eat better, I sleep better, I am more tired physically and it is good tiredness. You know, it's like you sit down and you think 'Oh yes!' [laughs]. And if I don't exercise now, I can tell the next day, I am going to be in pain.

Swimming is good as well. If I get a chance with a good hot pool or a hot country, I will swim and swim and swim. The exercise bike is 30 minutes a day, I watch Coronation Street – why not? You know it's 30 minutes of my life I will never get back [laughs]. You're going to be sat there watching TV, so I just get the little legs going. And also it is very important to keep the muscle tone. With arthritis, you tend to have a loss of muscle around the joint area. For me it's my knees, and for most people, it's the quadriceps that deteriorate. So that keeps them nice and strong, keeps the joints stable, less pain.

Evans: So is exercise suitable for everybody with arthritis?

Cumming: You should always get someone to assess you, and the best person for that is a physiotherapist. I am a big fan of physiotherapists. We have to explain to people that when they go to their physiotherapist and they get all these exercises, it's not just for the 6 weeks – actually, your exercise should be for life. They're just there to teach you how to do it.

Evans: And Jo Cumming's advice that you should always get someone to assess you before undertaking an exercise plan very much reinforces our message on **Airing Pain** – that whilst we believe the information and opinions 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 that knows you and your circumstances and therefore, the appropriate action to take on your behalf.

Now, Kate Llewellyn is Head of Information Services at Arthritis Care. She is responsible for the development of information they produce about living with arthritis.

Kate Llewellyn: The big issues for people living with arthritis really are pain, the fact that you often can't see pain. I myself have got arthritis and often get challenged because I have a blue badge, because people think there is nothing wrong with me. It can be very demoralising and upsetting to be accused of, sometimes you know, pretending there is something wrong with you

Evans: You look fine.

Llewellyn: The immobility, isolation, not being able to get about. The fact that it can affect friendships and relationships, it can affect your work. It can get into every part of your life which is why Arthritis Care is here, to try and show people that... to help them learn techniques or tips on how they can manage and make things better.

Evans: When I say you look fine I wasn't being patronising.

Llewellyn: Hmmm.

Evans: I was actually saying there is no outward sign to me that you have arthritis....

Llewellyn: Hmmm, hmm.

Evans: And, presumably as a member of the public, that affects the way I would deal with you.

Llewellyn: The worst experience I have had has been to do with parking and the car. I have a blue badge because I can't walk very far at all. Without my blue badge, I wouldn't be able to get out and about. One time, an old man – this is when I was about 17 – threatened to call the police on me. He was shouting at me in a public car park and just would not believe that there was any need for me to use the disabled space or use the badge. I was quite happy for him to call the police. It was dreadfully upsetting.

More recently, outside my home, I have had a disabled bay put in so, I can actually park – I live in London, so parking is always really difficult – and people have scratched my car because they don't believe that I am disabled. It's kind of a disability hate crime and it is really upsetting when something like that happens, right outside your house. You're worried about people coming to your house, threatening your space and there is not a lot you can do to prove it, unfortunately.

Evans: Kate Llewellyn. Now amongst the literature, Arthritis Care produces – and one of the many benefits of membership, as it happens – is a quarterly lifestyle magazine, *Arthritis News*. It's Editor is Minal Smith.

Minal Smith: At the moment, I am actually writing a feature on clothes and shoes. This is a problem that comes up a lot, on our discussion forums, where people find it difficult, you know, they might struggle with buttons, if they have problems with their fingers. It can be quite difficult to bend down and pull up stockings or tights, for instance. So, this article is looking at what the problems are and potential solutions. So that could be things like choosing things without buttons or choosing things with large buttons and there is also a number of aids available on the market.

But, it's mostly looking at what people can do, to help themselves and also looking at... obviously people with arthritis, you still want to be able to look good and have a choice. Unfortunately, the market is very much geared towards people who don't have those sorts of difficulties, so it is trying to find solutions that are stylish but practical and comfortable.

I think that clothes, in how you look, can have a big impact on how you feel. If you are stuck at home and you are struggling with simple things, like putting something on and then you end up putting something on that you don't really like or it doesn't really look good, then it is very easy to sort of sit there and say 'I'm not going to go out or do anything'.

We did a project a few years ago, looking at this issue. People did say then, things like using Velcro was a good solution; zips are easier than buttons; thinking about where a fastening is – so if something is at the back, it might be difficult to reach – you can buy garments that have side fastenings and that actually, is something you can find in mainstream shops as well, because it is sort of a style thing, so you can find that; choosing a jumper with a big neck so that it is easier to pull on. We have had quite a lot of feedback already through our discussion forums because you can really see what is on peoples' minds by what they are asking the others about and also our helpline team feed back to us on the kinds of calls they get.

Evans: Minal Smith, Editor of *Arthritis News*. The written word, be it on paper or online, is all very well but, when you want help and support and an empathetic voice to talk to *now* – then this is where the helpline, which Minal referred to, comes in.

Cumming: Generally, the first contact is somebody in considerable distress and they just need

to get it out, just need to talk.

Paul Evans: Jo Cumming is Arthritis Care's Helpline Manager.

Cumming: The majority of people want to know about the condition and understand it and often, they have been given a load of technical, medical gobbledegook from their GPs or their specialists and they need someone to help them find their way through to understand, you know, what the condition is and the treatment.

The next biggie – and it is only marginally smaller – is people wanting to talk about their pain. They want somebody to help them to self-manage and what the team will do, is listen to them, give an awful lot of empathy because they are all trained and qualified counsellors. So that is, in itself, for somebody who has lived with pain for a long time – they haven't been able to talk to their doctors, or their family even, about it. They are listened to but, more importantly, they are believed.

Evans: Jo Cumming. The Arthritis Care Help Line is open from 10am to 4pm every week day. The free phone number is 0808 800 4050 or you can email them at helpline@arthritiscare.org.uk. You will be reminded of all these contact details towards the end of the programme.

Now there are many misconceptions about arthritis. Here's David Walsh again, he is Director of the Arthritis UK Research Pain Centre.

Walsh: It is commonly thought that arthritis is a condition of old people. That is not true. It is true to the extent that any condition that currently doesn't have a cure, is going to be more common in old people, because we collect things as we go through life. But, arthritis, can affect people for the first time, at any age – so, children can have arthritis and old people can have arthritis.

I get frustrated, because I hear often, people talking about osteoarthritis and back pain as being 'degenerative conditions'. And 'degeneration' to me means 'wear and tear', like a car – the more miles you do in a car, the more bits wear out until you can't replace them anymore and then you get rid of it. There is a big difference between back pain and a car. A back is not wearing out – what is happening is, that it is constantly repairing itself and the changes that we see on the x-rays are a consequence of that repair process.

So, in fact, people are not wearing their bones out. People with back pain don't have thinner

bones, they actually have got more bone – you see extra bits of bone. Discs on the x-ray may look narrower but that is not because they have ground down like a washer in a machine – they are narrower because they have been replaced by something else that does the job that takes up less space. It is a bit like looking at your skin and seeing your scars and thinking that your skin is wearing out. It's not wearing out. You cut yourself, you get a scar, you know what's happened. It does the job, doesn't look the same, but there it is.

So these conditions, they are not degenerative, in the sense of a car wearing out. I think that is important, because it changes the way that you look at it. For your body to repair itself as well as it can do, it needs to be used, which is the exact opposite of wear and tear. The more you use a car, the more it wears out. By keeping using your body, it repairs itself better. Secondly, if it was wear and tear, then the older you got, the worse it would get, but in fact, that is not what we find – a lot of these problems, become a peak problem in late working life and then maybe become less bothersome as time goes on. It is not simply a case of 'ooh, you've got arthritis, therefore, it is going to get worse, the older you get' – it is much more complex than that. This isn't wear and tear like a car.

Lexi Barber: I am 24 and I have arthritis.

Evans: This is Lexi Barber. She is Editorial Coordinator for Arthritis Care. So you are 24, you look fit and very, very well [Barber laughs]. You don't have, what I associate with arthritis, which is the conker like knuckles. How do I know that you have arthritis?

Barber: You don't – that is the trouble. It is one of those invisible disabilities. The classic image of the painful hands is very misleading, because it can affect any joint and it can affect anyone in any different way. If you were to look at me, you wouldn't know, but it is because mine's in my knees, so if you were to watch me walk over a longer period of time, you would realise that it is a struggle, but you wouldn't necessarily know why or you might just think, I am really lazy.

Evans: So, how does it affect you?

Barber: You just have to, kind of, rely on your friends and make sure that they know, that you're not just being difficult when you say 'Can we not go to that pub because the toilets are up two flights of stairs, and I don't want to have to keep going up and down cause I know we are spending the entire evening here'. You have to know that they will adapt to you and not be afraid to communicate that with them, but at the same time, not come across like a

hypochondriac.

Evans: So there are two things here: they have to be... [pause] ...I was going to say sympathetic, but not sympathetic – empathetic... **[Barber: Yes.]** ...to your condition, but you also have to be able to explain to them what it is all about.

Barber: Yes, definitely and my close friends definitely have picked it up, so I don't need to communicate it to them anymore. They can tell when I am having a bad day and they have learnt to filter in rest breaks without making a thing of it, whereas, at first, it was very much like 'Do *you* need to sit down?' And because that put a responsibility on me to slow everyone down, I was just like 'No, no, I'm fine, let's carry on' and then I would pay for it the next day. But now they are all like 'Let's all sit down for a bit'. And they don't make a thing of it, so it is definitely about give and take with communication.

Evans: But that is good friendship isn't it?

Barber: Yes, definitely. It's taken a while to get there as well and I do still have a few people who just look at me and think 'Oh, there's nothing wrong with you, you're young'.

Evans: 'You're looking better'....

Barber: 'Oh, you are looking better' is one of the worst things someone can say. They mean it as a compliment but, actually, I'm like 'I might look fine but I *really* hurt right about now'. And you just sort of get used to it, biting your tongue and getting on with it, most of the time [laughs].

Evans: That was Lexi Barber. Kate Llewellyn developed arthritis, when she was only 13.

Llewellyn: I had to have a year off school because I wasn't able to physically get in to school and cope with day-to-day life really. I became, I now realise, depressed and very isolated from my peers. You know, when you are about 15/16, it is a really important time to be learning about who you are, so it was, very challenging, to be running around, to be on the netball team, to be a hurdler and then suddenly, to fall over the hurdles and not know what is wrong with you, which is what happened to me.

I was lucky to be diagnosed, quite quickly. It does stop your life. It stops you becoming the person, you thought you might be – but also, for me, developing it as a teenager, it has allowed me to then shape my life, to still to do something, I am exceptionally proud of. And something that I am interested in. What is difficult, is that people just always go 'Oh you are too young to

have arthritis' and you spend your life going, 'actually, no I am not'. Babies can be diagnosed with arthritis. It can happen at any age to anybody. Having to justify it, is like an extra thing of explanation, just to say 'It's true, I really do have it and it affects me significantly'.

Barber: We have recently, just produced a new booklet for parents of children with arthritis, in terms of the challenges they might face, as they are diagnosed and also, the strategies that people use to cope with family life. When your child has arthritis, it can impact on the whole family.

To begin with, if they are diagnosed very young – so when they are still babies or toddlers – it can be difficult to get a diagnosis, because there is a communication barrier straight away that their child can't tell them what hurts and how much it hurts and why it hurts. So, the parent has to be quite vigilant in looking out for signs, such as swelling. When they do take them to the doctor, a lot of the time, it can be misinterpreted as just having a knock, from being too aggressive when they have been playing or they have fallen over or something.

Then as you are growing up, it's simple things, like if you have other siblings, you have to learn how to let them understand how arthritis affects their brother or sister, so they may not be able to play rough and tumble as much or they might not be up to family outings in the same way. Also, in terms of attention, obviously you need to look after your child who has arthritis, but you also need to make sure that your focus is fairly split, as it were.

You also have other things such as, informing schools that your child might not be able to do PE every day or that they might need regular breaks from sitting or that they will need more time off than most children to go to hospital appointments and everything. So, it is about communicating with who you need to inform about your child's arthritis and how it will affect them.

And as they grow up and become teenagers, there's the usual thing of how much independence to give your teenager and when your child has got arthritis, you have to take that into account – you want to give them more independence over things like, how they choose to take their medication, they might want to discuss taking it in a different form, or having a different routine, or taking charge of it themselves, rather than being given their medication. It is all about letting them find their independence, while realising that they do have to adapt for their condition as well.

The independence thing definitely shows up more when people are looking at colleges and

university. When you are letting them move out, you have to take into account that they are going to be looking after themselves – it is quite hard for a lot of parents, I think.

Cumming: It is rare that you get osteoarthritis when you are younger. The kids with the juvenile form of inflammatory arthritis – it is hard to diagnose, it takes a long time, so the parents get really quite anxious about it. They say ‘Why couldn’t they tell us this earlier?’ Well, it is hard to diagnose because it could mirror so many other juvenile illnesses and it is difficult to know with kids.

The pain for children – because for many of them, the symptoms come on when they are toddlers – they live with pain all the time and they think everybody else does. A friend of mine’s little girl said ‘Well I thought, it hurt everybody to walk upstairs, I didn’t realise. I thought that everybody felt pain walking up the stairs.’

And they tell us a lot of interesting things about coping with pain and understanding pain. When you see it through the eyes of children who are actually, living it, everyday, and the mums and dads have to help them exercise and move those painful joints, it is a real eye opener and *it is moving*.

The person who we always get in to train the team about parents and about kids is Dr Carrie Britton and she wrote a great book called *Choices: kids with arthritis*. She can really explain from a parent’s point of view and she showed us – and it was excruciating to watch – she actually videoed herself helping her little girl to exercise and the tears and the pain – we were like ‘oh, ooh...’ there was not a dry eye. But it has to be done, you know, you are doing it for your child but you are hurting your child. But you are doing it so that they’ll have a better quality of life later, but it is hard for the kiddie to understand at that point, why this has to be.

When you have a child with a chronic condition, it’s not just the pain, you have that extra... just take going out for the day – the extra thing of the medication, the packing, the getting everything organised. We work quite a bit with families in Arthritis Care and we have adventure breaks for the children, where they can get out and abseil down a mountain. These are kids that probably a lot of society has written off, but then you see them, and they are out, and they are doing the things that other kids in the class can do and they get a chance to do it and it is *great*.

Evans: So for parents, who are struggling by themselves and need somebody to talk to, or *anybody* involved with somebody with arthritis, they should phone the Arthritis Care helpline?

Cumming: Yes. We will send them a free pack of information, actually tailored to what they need to know. We will talk to them and it doesn't end there – if they want to ring again, they are most welcome. We have groups, we have self-management training courses – they can all access these free. It is just the first step for many people.

Evans: And how do we get in touch with you?

Cumming: You can ring us on 0808 800 4050. It is a free call, we are open Monday to Friday (10am to 4pm). You can write to us, you can email us at helplines@arthritiscare.org.uk or you can get online and chat to helplines on the forum.

Evans: Jo Cumming, Helpline Manager of Arthritis Care. Arthritis Care also run a series of self-management programmes throughout the UK and I have just completed the challenging Pain workshop in Cardiff – it's for people with all chronic pain conditions, not just arthritis and you can hear how I got on, in the next edition of *Airing Pain*.

Now today's programme came out of a very straightforward request from Judy on our message board, so if you would like to put a question to our panel of experts or just make a comment about these programmes, then please do so via our blog, message board, email, facebook, twitter or pen and paper. All the contact details and links to download all editions of *Airing Pain* are on our website which is Painconcern.org.uk.

And for more details of Arthritis Care, their website is arthritiscare.org.uk. Now, the last word in this edition of *Airing Pain* goes to Lexi Barber and I think it applies not just to people with arthritis but to all of us with persistent pain.

Evans: For somebody, early twenties, late teens, what would your advice be to them and their parents and their friends?

Barber: Be open about it because, people can't always see the problem. And try and communicate it in a 'I have this. It causes me a problem in this practical way and this is how we can avoid it' because people are far more responsive if you are trying to communicate a practical solution rather than just going 'Oh no, my knees really hurt today'. They might not understand how you feel pain, because everyone feels pain differently, they might not understand how it's an ongoing thing, but if you say to them 'my knees really hurt today, so can we take the bus instead of walk? Can we do this, instead of this? – it helps to open up communication pathways, rather than just being the one who always comes across as always

saying 'Oh, my knees hurt'. It's important to be open and ask for help when you need help.

Contributors

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