

Airing Pain Programme 40: Children in Pain

The pain management needs of children and young people and the impact of their pain on family life.

This programme focuses on pain in children and young people, including the different needs they have and the unique challenges that their care presents compared to adult patients. Paul Evans and Christine Johnston talk to experts at children's hospitals in Edinburgh and Glasgow about the strategies they use for helping young people to cope with pain.

Although there are obvious differences between treating an infant and a teenager, the aim is always to enable young people in pain to live the fullest lives they can, while minimising the effects on their education and socialisation. We also consider the wider impact of a young person in pain upon the family unit and we hear from Sam Mason about how chronic pain has impacted his life at home and at school.

Paul Evans: Hello. I'm Paul Evans and welcome to **Airing Pain**, a programme brought to you by Pain Concern, a UK Charity providing information and support for those of us who live with pain. This edition is made possible by Pain Concern, supporters and friends. More information on fundraising efforts is available on our JustGiving page.

Jean Eadie: If you have a sick child, I think the parents have to come to terms with it, because they're living with it constantly – they're usually distressed quite a lot of the time.

Pamela Cupples: Parents by definition want to make their children feel better and feel powerless to a certain extent with chronic pain because the paracetamol or the non-steroidals [non-steroidal anti-inflammatory drugs] that they've been given which *should* take the pain away *don't*, so they feel helpless. Unfortunately there's lots of kids out there who have chronic pain whose families are going through this on a day-to-day basis.

Evans: For those families who *are* going through this on a day-to-day basis – this edition of **Airing Pain** will visit two hospitals in Scotland that treat sick children. First, I went to the Royal Hospital for Sick Children in York Hill, Glasgow, where I met Consultant Physiotherapy Manager: Jean Eadie and Anaesthetic Consultant: Pamela Cupples. And she (Cupples) explains the difference between treating adults and treating children.

Cupples: I think there's a lot of overlaps but the big difference is that emotionally you're dealing with children who are ranging from the very young to the adolescents and it becomes a package: they're coming not only as themselves but they're bringing their parents. And, understandably, if this condition has been going on for a long time the parents

are very anxious and concerned about this child – that they're unable to help manage their pain – and you mustn't forget that there maybe will be siblings who are also affected by this. So it's not only the child but the family that are affected by the condition they are presenting with.

Evans: So the impact is on the whole family unit?

Cupples: Without a doubt.

Evans: A 4-year-old child will have a 7-year-old brother.

Cupples: Without a doubt, and with a lot of focus being on the 4-year-old child, you have to remember that there's the siblings – whether they are younger or older – who will undoubtedly be affected by the sibling with the chronic pain.

Evans: Jean, at what point do you see the children? You're a physiotherapist, physiotherapy for children can't be the same as physiotherapy for adults, can it?

Eadie: No it's an absolutely, *totally* different, a totally different approach altogether: as Pam says you're really treating the whole family. You have to get trust from the child, you have to really [get them to] have faith in you, believe them that they've got pain, because sometimes, by the time we get the children, they've been all round, all over the place, been sent from here to there and nobody is giving them any answers. So the first thing that I would do is reassure them – we know you've got pain, we're here to help and it'll take time – we have to explain it all to them. Now some of the children, I tend not to see the younger ones – they have different issues. Probably the most we see are the adolescents or from 10 to 14 and it's mainly girls, so for whatever reason it is – there's sometimes something else going on – which because we work as a team with psychology, psychiatry and the anaesthetic team, it's very important that we're all saying the same things to these children and gaining their trust.

Evans: Do you know why it's mainly girls?

Eadie: There have been questions asked about hormone imbalance or this transition from primary into secondary school that is the most common with girls now. They haven't looked into it in great depth but it's always at the back of our minds. Sometimes perhaps it might be the girls aren't coming up to expectations with some of their peers – who knows? But sometimes there are issues like that or there may be issues at home. I don't know if you agree with me Pam – what do you think?

Cupples: Without doubt! It's a very difficult time period, that transition into puberty or about to enter into puberty, and difficult things may be happening with the child. They may have

had an injury, but there may be things going on in school or within the family, and it manifests itself in a different way and they can present at a chronic pain clinic. And as Jean said, it's very important that we have a multidisciplinary approach and we value all the input that we get from all the disciplines – physiotherapy, psychology and psychiatry – and it is a group effort.

But the most important thing is reassuring them that they are not alone and there are lots of other kids out there who are experiencing the same problems and the same pain, and that we believe them and that we are going to try and help them and certainly get them on the path to recovery. And if in an ideal world we get rid of their pain, but if we can't get rid of their pain we give them techniques to cope with their pain better and allow them to get back into normal life, stabilise life and start socialising, getting back to school – all the things that kids of that age would normally be doing.

Evans: Pamela Cupples and Jean Eadie at the Royal Hospital for Sick Children in York Hill, Glasgow.

Fifty miles to the east is the Children's Hospital in Edinburgh where Consultant Anaesthetist Mary Rose runs the chronic pain clinic for children.

Mary Rose: I'll been seeing children from the age of five upwards with chronic pain. And it's the time of their lives when these children should be receiving schooling, should be really developing social relationships and things. So if they have chronic pain that can have huge impacts on their schooling and their psychosocial development which could really impact on into adulthood. So this is a really crucial time to try to improve their function if they have chronic pain and it's affecting their function. The overall treatment approach is still multidisciplinary and a bio-psycho-social model that we use for treating children, but just an age-appropriate model.

Evans: What do you mean by bio-psycho-social?

Rose: The children that we see – I always feel that their pain will have a biological cause but there will also be psychological and social factors that will be impacting on their pain as well. And it's also a two-way model – I think the pain itself will cause biological problems and can cause psychological and social problems for the children so it's very much a two-way process.

Evans: Now I'm not saying that children are more special than adults, but some of the social problems you've just mentioned – the education, learning to live with other people – all the learning processes through life as a child. These cannot be missed, can they?

Rose: That's right, so it's really a one-off opportunity, I think, for these children to develop these social relationships and to acquire their education that's going to affect them all the way through adulthood. I think that's why it is so important to manage these children and improve their function. We say to them we can't always... we don't expect to get their pain scores down to a zero, but we do very much focus on improving their function.

Evans: Having a child in pain can be one of the most upsetting things for a parent. How do they deal with it?

Rose: As you say it's very distressing to see a child in pain and some of the families, they can be angry. They can feel very frustrated that nobody's doing it and on a practical side of things a child may not sleep if they're in pain. And so their child will be going to sleep with the parents and nobody in the house is getting to sleep, and the parent will end up not being able to get to work because they're tired or they're having to stay at home to look after the child. And so it has a massive impact on them.

Evans: And I suppose you could lose confidence as a parent: 'Do I rush my child into A&E or do I just stay home? Do I have the confidence that they're OK?' What advice would you give to parents?

Rose: Yeah, it is hard for the parents. I think we would start off by giving them an explanation of why the child has the pain and then give them advice on how they should manage the child which will often include, yes, acknowledging that the child is in pain, but then trying to move on and perhaps distracting the child and trying to carry on with life rather than everything going on hold because the child has pain.

Evans: How do you talk to children or adolescents about pain? Because as an adult I might be able to communicate with you much better about what I'm feeling, how I'm hurting, how it's impacting on me, but a child might not be able to communicate the same way.

Cupples: I agree – it's very difficult for very young children to put into words what pain feels like. When we get a referral to the chronic pain clinic we actually send them out our pain questionnaire which gives us a lot of background information about who they are, who's in the family group – so brothers, sisters, mums and dads. And then there's a page where there're a lot of words that we would use to describe pain varying from throbbing, stabbing, aching and they have to circle the words that best describe their pain and they then have to choose three words that they can whittle down to being the words that describe their pain best. That's a very useful tool for us because it allows us to try and get that description of pain which is much easier in adults, but very difficult in children.

Evans: Do children understand everything you're talking about?

Cupples: I'm sure they don't, but I think we're very aware that you're dealing with an age range of children, and you have to be age-appropriate, and so the terminology that you use for a 14 year old is very different to the terminology that you would use for a 6 or 7 year old. So you try and use words that they understand and it is important that they *do* understand what you're talking about. Obviously the dialogue you have with the parents is very different, but it's important that the child understands why they're there, what you're trying to do for them and gets a sense of ownership.

Evans: Give me an example – how would your language change talking to a 5 year old as opposed to talking to a 55 year old?

Eadie: It would be different for me in that the treatment, or whatever I was doing with them, would be more play. Just playing with toys, watching them, observing them, seeing what they're doing and just talking to them as you would to any child – about what they've been doing, what they like and 'What did you have for your tea?' and just normal chit chat. So you wouldn't be asking them adult things about anything; it's just more play and just normal things you would talk to a child about.

When you get to teenage things, its more on a social level about what they like to do again but in different ways. But it's just a wide spectrum of stuff that you do discuss with children. And you have to see what responses you're getting from the child because if they don't want to talk to you then they won't and if they're in a huff, fine – but you can't keep push, push, pushing them. They're in a very strange situation and in hospital with a lot of strange people asking them questions, to take their clothes off and all the rest of it, you know, so you have to be quite sensitive to their feelings and their needs as well. And if the responses you get from a child are just horrendous then you may as well just stop – go away and come back another day.

Evans: Do you find that teenagers are difficult to work with?

Eadie: I think they either love their physio or they hate them and to be honest there's not much of a happy medium there. And it is very difficult because sometimes you have to say to them 'Now look, it's going to be a bit uncomfortable'. We try to relieve the pain obviously but we have to explain that it will be uncomfortable and a bit painful, but that's the way you're going to get better, and in the main they come round. But you do get the occasional one that's quite difficult so... but there haven't been many failures.

Evans: So at the end of the day when you finish the course of treatment, what is your ideal outcome?

Eadie: That they just go back to normal life. I mean, that's the bottom line.

Consultant Physiotherapy Manager, Jean Eadie at the Royal Hospital for Sick Children in Glasgow.

Evans: Sam Mason suffered a burst appendix when he was eight. It left him with chronic pain for which he's been attending the Chronic Pain Clinic for Children in Edinburgh for the last 5 years. Christine Johnson went to meet him and his mum, Lynn. She started by asking him whether it was difficult to describe his pain to the doctors.

Samuel Mason: Well at the beginning it was but eventually we developed a way of saying whether it was sharp pains or achy pains, and a scale that we used from 1 to 10 and smiley faces. When you have a cough or something and it's just a little tickle in your throat and it starts to hurt a little bit, that's kind of the 1, and it goes through a scale. Five is when you're starting to feel upset and 10 is when you're crying in agony. The majority of the time it's a 7 or 8. I heard a little girl in the next bed to me when we were in the ward. She said 'I feel it's a 10' but she was actually a 4 and the thing was... it's a good thing, but I think sometimes kids can get confused with it. I heard [this] from just sitting in the bed and hearing things and just wondered why that was. The next day a play nurse came and explained to them what the system was and how it worked and I think that if all the kids had that, it would give them a much better understanding. Because then I noticed a boy over from me, who wasn't feeling that well either, and he had the system explained to him and then they could actually deal with it in the right way, I think, because he felt better after a couple of days. And I just thought it was good that they had that.

Lynn Mason: The other thing was that Samuel looked quite well and he didn't think people believed him, and sometimes I would think 'Oh come on, it can't be that bad!' so it's very difficult. I think the more you live with it, you actually see the effects – the knock-on effect – it has on his life and you realise that a lot of it can be psychological too with the pain. He couldn't do a lot of things that he would have been able to before. So I think as a family it has a big impact on everyone – you know – and on what we used to do at weekends, depending on how Samuel was feeling.

Samuel: I think it had a big knock-on effect on my sister, though, because she normally had a fun brother that would always do things with her, so she was quite upset a lot of the time if

I had to spend – say when I came home from school – a day in my bed, just until after teatime, until I could actually do something at all.

Christine Johnson: So is she older or younger than you?

Samuel: She's younger than me – she turned 10 in June – so it was really hard for her because when I first started she was about 7. So she was at that kind of age where she always wanted to play and never wanted to rest, so it was always hard for me to actually say no. Cause I wanted to, but I knew if I did I wouldn't be able to do anything the next day. You know these kind of rip apart Barbie dolls that you have? I think at one point it got so hard to tell her what was wrong that I would show her here what pain I felt and use a red marker pen to show her how bad the pain was, and she would ask me how bad it was and we would have a colour scheme and stuff like that.

Evans: Sam Mason. Whilst many of the same drugs are used to treat children as *adults* with chronic pain – of course in an age and weight appropriate way – Consultant Anaesthetist Mary Rose points out that the use of medication is just one part of the treatment.

Rose : In addition to medication, we'll also use TENS (transcutaneous electrical nerve stimulation) machines and ENM (electrical nerve model) machines and use acupuncture as well – which surprises some people [laughs] that the children will accept it. But the majority of children – again, once we've discussed it with them, shown them the acupuncture needles – are happy to undergo the treatment.

Evans: Do they respond well to it?

Rose: Some children do, yes. I tend to use it for children with headaches or children with muscular-skeletal back pain – it can be quite effective there. When they have acupuncture one of our specialist nurses does the treatments and she'll certainly initially do a weekly course for 6 weeks. And I think the children enjoy very much meeting with Mandy every week as well [laughs] which is one of the reasons why it helps.

Evans: Meeting with Mandy who is going to stick needles in your back.

Rose: [Laughs] Mandy is a very warm friendly person who gets on very well with the children and so they enjoy coming [laughs] to chat with her.

So Christine Johnson's off to see Mandy – that's Mandy Sim, one of the pain nurse specialists at the Sick Children's Hospital in Edinburgh – and she's been treating Sam with acupuncture.

Mandy Sim: Our normal sessions would be a course of six appointments, where I would see them every week for 6 weeks. Usually you'll start getting effect on about the second or the third treatment and ideally what we're looking for is that the effect is sustained longer after each appointment. So then, hopefully, by the time we get to session six they've got a good sustained effect from their acupuncture and then we'll bring them back for top-up appointments as and when required thereafter. The first appointment, I might only stick in one or two needles, depending on what the child is able to cope with, and then building up from there. Obviously where the needles go in depends on where the child has got pain. Needles are usually left in for approximately 20 minutes.

Samuel: When you put the needle in sometimes you can feel a lot of what is called 'Chi' – the bad energy that comes out – and so you can feel the flaring and the redness that becomes itchy. When I had a lot of pain that would happen *all* the time, but now it's just like a reliever from any extra pain that you've had on for the past 2–3 weeks.

Johnson: How long from when you started the treatment do you think it was until you started to feel a bit better, that you could feel it working?

Samuel: Personally, I think it took three sessions at least to get an effect of it because it took a while to build up – you know – having no pain. I think the first time I thought 'This is just sore, why are you doing this to me?' [Laughs] So it did take a while to get me into the way of thinking that it is going to help.

Sim: With chronic pain for children, and probably for adults as well, a lot of the time we're not looking at high pain scores or getting somebody down to having no pain because that's just not practical. What we try to look at is level of function – are they getting to sleep? Are they getting into school? Are they able to socialise with their friends and do normal things for their age group and normal family things? So that's what our aims are within the Chronic Pain Clinic: to give the child their life back.

Lynn: The first time he had it he got in the car and instantly started yawning and was very tired. Mandy had said he would be very thirsty so we had juice and he finished it all and we had to stop and get more, so he was very thirsty. [We] got him home that night [and he] managed to get to sleep quite quickly, which he hadn't been able to do. I checked on him and he hadn't moved at all in the bed and so he got a really good sleep. That was the first time having done it and so after that I was very keen for him to carry on because it was obviously quite – not that he maybe felt it from the pain – but from the general problems with his sleeping and getting to sleep at night, it worked quite instantly. And he never moved – he's a real mover in the bed, you can hear him – and he didn't move. I went up in the

morning to wake him for school and he was in exactly the same position – which he's not on other days when he's not had the acupuncture – so it was very interesting from that point of view. And he woke up a much better colour in the morning because he'd got to sleep earlier, but also it had obviously done something to whatever was going on in his body as well.

Samuel: So I think that's what it was – 3 weeks it took – because after 3 weeks I actually realised 'Wow! I've had a really good sleep, I can do more'. So I started to build up my normal schedule – I would get back into doing a lot more because of that function.

Sim: There's a lot of children who have had chronic back pain in the past and they are now able to start going back to dancing classes that they've maybe done before, participate in sport that they've not been able to do for a while. We've had some teenage girls who were able to go and get themselves a part-time Saturday job. As a teenager, you don't want to be different from your peer group and you don't want to be taking medication where it's obvious at school that you're going down to the sick room at lunchtime to take medication. So if it's something that's not making you stand out from your peer group it's really useful.

Samuel: The biggest difference I noticed is that when I have PE [physical education] at school, I'm not having pain in my back – it's mainly my back that I get the pain in and that's where we normally do most of the acupuncture – and it's just been much easier to do the PE instead of having to say 'Can I not do this one because of the pain in my back?' And I can also come home and then do something else and not just have to come home and rest because of the pain I've had to deal with all day.

I think I'd like to say one more thing though – it's about primary school, just in general – because when I went back it was really hard to get back into doing anything and there was a lot of challenges I felt I had to overcome which was actually – get past everyone asking me how I was every single day. When I couldn't sit down on a proper chair and I had to have a cushion or something, people weren't happy with that. And so it caused riots in the class, because they weren't happy with me being the only one with a cushion on the chair, and so they would fight over who would get the spare cushion that was in the classroom. So they'd have this fight and I felt like it was my fault but [I thought] 'I can't help that because I have to do this otherwise I can't sit down'. And then there were a few teachers that weren't really ...

Lynn: But Mandy sorted them out.

Samuel: When Mandy came in and had a little talk – she did a little presentation – she did it in a way that no one knew that I knew Mandy. And so when she was talking about this pain machine that I had – the one that vibrates – a lot of people pointed out that I'd had that and

that kind of made them more interested, rather than jealous that I had all these special things. They were more interested when they realised how much pain I was actually in – I think that kind of helped them all to realise. It gave me my life back in a sense because I could do everything with my friends.

Lynn: We'd be lost without it, wouldn't we? Acupuncture's been a good thing – as a parent you don't feel like 'I'm putting more drugs into my child'. Which do help to a certain degree but it is good to have something that is drug free and that Samuel can get some instant relief and get a good sleep from.

Johnson: Are there any other therapies you found particularly useful?

Samuel: Well there was one that we got introduced to because I was having trouble getting to sleep in particular. It was a psychologist that gave me techniques like breathing in and out and you imagine that you're filling a balloon and eventually the balloon would burst and that would be you relaxed. And she was also very helpful because she would help my mum as she would tend to have – no offence – crying fits [laughs] because the pain got stressful at times. It was really Katie that helped us – she always used to have tissues in the room because it would help [laughs]. Eventually when she got her calmed down, she could give everyone else techniques to calm [them] down as well.

Katie was very helpful as well because at the time I was in a Star Trek phase and so we made up our own technique: when you're calming down you were the commander of the bridge and you would go and say 'We've got to drop off the cargo' and your cargo would be your stress and everything that would build up. And the pain would go and then you could put the ship into light speed and go to sleep.

I went to a group once and there was a group of people – there was one that was 18 and one that was 16, me when I was 11, another that was 14 and another 17 year old. It was a workshop and it was someone that would teach you a wider variety of techniques. We made a happy box and you would put things that would make you happy in there, and so we put in all the techniques that Katie had given us because she had given us a big folder so we would never forget them, and we could read over how to keep yourself calm. I put a few other things in, like my pictures of happy times with my family and everything, and some things that we would want to get back to. I used to always have a bar of chocolate in there so, when I was feeling a bit down, I could have some chocolate and read over these things and it would make you happier. We also made a pillow that you had all your happy things on and I put some lavender scent on it so it calmed me down before going to bed as well.

Johnson: Was it helpful doing it as a group and meeting other people and seeing how they cope?

Samuel: Yeah, it was actually. The 18-year-old boy was saying that a lot of the time he just feels like crying, but he could never really cry and his eyes would just water up. And he found that very hard as a teenager because he liked to play music and you know music is... you're supposed to be...I wouldn't say 'a tough man', but a lot of the time, with the pain he felt, he couldn't cry because his family would then think other things and he wouldn't be happy with that. But this workshop taught him to just be comfortable and be himself, and if he had pain to talk to his family about it. After a couple of these sessions he came back and you noticed a real difference, with his dad especially. His dad has been struggling to cope with it – you know, macho man he said his dad was – and he was struggling to cope with the fact that his son wanted to cry because he was in so much pain. By the time he left he was so much happier and wasn't all doom and gloom.

Sam Mason with a refreshing lack of doom and gloom – just what the doctor ordered. Now every week I issue these words of caution that whilst we 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 well-being. He or she is the only person who knows you and your circumstances and, therefore, the appropriate action to take on your behalf. But what should parents do if they are convinced that their child is in pain, but feel like they are being ignored? Mary Rose again.

Rose: That's a difficult situation, the way the health service is set up in the UK, it's very much a case that you must go through your GP [general practitioner] and be referred to a consultant. I think they would just have to be persistent and be a nuisance to the health services – not necessarily asking for more investigations, but the child has a right to have pain management.

Evans: But they need to be confident, well I use the word pushy, you use the word persistent, it might be different, but they have to stick by their guns.

Rose: Absolutely, yes. If it were my child of course I would be persistent and yes, you may be perceived as being pushy or difficult, but you have to do what you feel is best for your child.

Evans: But keep at it.

Rose: And keep at it, yes. And there are contacts such as the British Pain Society. If you feel your child has a chronic pain syndrome – you may have looked on the internet and feel your child has a complex regional pain syndrome or something – there are contacts with the British Pain Society who would be able to put you in contact with a pain specialist that you could then ask to be referred to.

Evans: But?

Couples: If we had a magic bullet or a magic wand, we would use it in clinic. But we have to explain that many of the things that we're doing in chronic pain take a long time to develop their effects – that it's not like an adult has a headache, they take a paracetamol for it and 20 minutes later the head pain is gone. Chronic pain is very different and it can take a couple of weeks before you get a feel for whether the medication that you've started is going to be effective, or whether the TENS machine is going to be useful, or whether the acupuncture courses are going to be the solution to the problem. So it's managing their expectations and making sure that you reassure them that you believe them, that you have lots of other specialists to help in the management of their pain and help them deal with the pain, and that over a period of time you will either hopefully get rid of the pain completely. And, as Jean said quite rightly, our ultimate goal is a pain-free child who is back to school and not missing chunks of school, which we see quite often in chronic pain, and who is socialising normally and developing normally. [Or] sometimes we don't get rid of the pain completely, but if we are able to get that child back to school and functioning normally and give them techniques where they are able to cope with their pain better, then that is still a kind of win in our book.

Evans: That was Pamela Couples, Anaesthetic Consultant at the Royal Hospital for Sick Children in York Hill, Glasgow. Now don't forget that you can still download all the previous editions of *Airing Pain* from painconcern.org.uk and you can obtain CD copies direct from Pain Concern. 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 and of course pen and paper. The contact details are at the Pain Concern website – once again that's painconcern.org.uk. The final encouraging word to Consultant Anaesthetist Mary Rose who runs the Chronic Pain Clinic at the Children's Hospital in Edinburgh.

Rose: Children have remarkable powers of recovery and I'm optimistic that if we can manage them, that – even if we can't completely get rid of their pain – they will be able to live with their pain and acquire their schooling and get out, get their social contacts. Also, another key message would be that the management of chronic pain, it is very multi-

disciplinary, I think drugs are only one very small part and, although I am an anaesthetist and drugs is what I do best [laughs], I recognise that drugs are actually only a tiny part of getting children better. The psychology and physiotherapy – the physical approach is as well really important in getting children of chronic pain better.

Contributors

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