

Airing Pain Programme 3: Children in pain

The hidden problem of pain in children and young people, plus tributes to Pain Concern patron Claire Rayner.

Chronic pain is as widespread in children and young people as in the population as a whole, but is probably even less well understood. Jan Barton and her son Sam, who grew up in constant pain, discuss their struggle to get a proper diagnosis and to find effective treatment, while, Dr Christina Lioffi explains how hypnosis can be particularly valuable as an approach to managing pain for children. Dr Amanda Williams describes the psychologist's role in helping patients manage their pain and Dr Tonya Palermo explains how a psychologist can explain pain to young people.

We also pay tribute to the late Claire Rayner, indefatigable campaigner for patients' rights and patron of Pain Concern, who died October 12, 2010, aged 79.

Lionel Kelloway: Hello and welcome to **Airing Pain**, a programme brought to you by Pain Concern, a UK charity that provides information and support for those who live with pain. Pain concern was awarded first prize in the 2009 Napp awards in chronic pain, and with additional funding from the Big Lottery's funds awards for all programme and the Voluntary Action Funds community chest, this has enabled us to make these programmes.

I'm Lionel Kelloway and in today's programme:

Sam Barton: I was told, this is how you're going to be, you're going to have to put up with this for the rest of your life and that was a destroying moment for me.

Christina Lioffi: Chronic pain is actually quite common in children and adolescents, with prevalence rates that mimic adult prevalence rates.

Tonya Palermo: The main factors that I have found that predict how good somebody will be is their dedication and commitment to learn hypnosis and how motivated they are.

S Barton: I got to the point where I even said, 'Look, amputate my leg. If it's gonna help, just take the leg off.' You know, I'd rather have lost the leg than continue.

Kelloway: More on those stories coming up. But first we at Pain Concern want to pay tribute to our patron, Claire Rayner, who died recently. Many words have been said since her passing and I think the best tribute we could pay is to hear the advice she gave to **Airing**

Pain listeners earlier in the year. You'll also hear the words of Pain Concern's chairman Heather Wallace and Martin Johnson, who chairs the Royal College of General Practitioners pain management group.

Claire Rayner: One summer night I'd gone to bed early and was lying in bed stretched out starkers, reading, glasses on the end of my nose, and my husband comes in, he stands beside the bed and he says, 'Look at you,' he said, 'you've got artificial shoulders, artificial knees, you've got hearing aids, you've got a pacemaker, you've got glasses – I don't know whether to plug in or switch off!'

Heather Wallace: Claire Rayner was an inspiration – she challenged the view that nothing could be done about pain and suffering. She also championed the rights of older people and the notion that pain was an inevitable part of aging. She herself endured considerable illness and pain – she didn't let her disabilities hold her back.

Rayner: This arm, it's alright, but I've learnt not to try and lift myself up with it. I've learnt not to stretch with it – tricky because it's my right arm, but there you go. And I shake hands when I meet people – I put up my left hand to say, 'Hello, it's lovely to see you.' And they're a bit startled at first and I say, 'Sorry, the other one's a bum! [Laughter] and there you go.

Just be cheerful about it. I'm deaf as a post. When I meet people I say, 'You'll have to speak up love, I'm a bit mutton.' You know the term 'Mutt and Jeff'? Good old cockney, you know, Mutt and Jeff, I'm a bit mutton.

You've got to be brave and upfront. Do remember that once you're an old grown up person, you don't have to be polite and good anymore – you are allowed to be selfish, if that's what you think it is. I don't think it's selfish, I think it's common sense to look after yourself. But you're allowed to ask for what you want, you're allowed to say, 'Please help me.' There's no loss of face in that, I do it all the time.

Martin Johnson: Claire Rayner was the most dedicated peoples' champion that I've ever met. Even throughout her illnesses over the last few years, she's been so dedicated to doing work for patients. It was a privilege to work with her. I am a trustee of the Patients' Association, she's spearheaded the National Patients' Association for many, many years, and I can't think of anybody that has done more for patients' rights than Claire.

Wallace: She wanted people to learn about pain and about pain management, so that they too could manage their condition and get on with their lives and get the most out of their lives. She was an empowering woman and we will miss her greatly, we will miss her voice, her energy and her influence on health policy.

Rayner: You deal with pain by... you have to be rational about it: is there anything you can do to get rid of it? Yes – do it. Is there anything you can do to get rid of it completely? No – okay, bad luck, live with it. And that's what you have to do, you learn, I learned, not to think about it, not to focus on it. When I find I have a pain that bothers me more me one knee I will start flicking my fingers, even as I'm watching television, because that makes me shift focus of attention from the achy bit to a bit that isn't aching. And that works quite well. I don't do it... if I do it in the cinema people might notice, but even there if something hurts I might flex my toes, because that shifts my physical attention to another part of my body.

One of the best things you can do is get in touch with the specific [support] group, they're all there, use them, and then just get on with living your life. And if you've been dealt a bum hand, well you can turn it into something good.

Kelloway: The much missed, inspirational Claire Raynor, who amongst many roles was patron of Pain Concern. I'm Lionel Kelloway and you're listening to *Airing Pain...*

Sam Barton: I was about eleven years old. I noticed I had two distinct lumps on my calf. Within a couple of months of noticing this I started getting pain symptoms in my calf and within another couple of months I was in absolute agony. After that we obviously went through the whole palaver of meeting doctors, surgeons, trying to work out what it is, going for scans. The original decision, I think, was they thought they were lipomas. They operated and found that obviously what they were operating on was not lipoma at all and the operation subsequently had the effect of increasing the amount of pain I was in.

Jan Barton: The lesion in Sam's leg, which was an abnormal vascular lesion, was putting pressure on the nerves in his leg and there was no cure at that time. And he was in agony when he was young, he described it as like someone poured petrol down the back of my leg and set it on fire and I think that set the scene for the next ten years.

Kelloway: That's Jan Barton and her son Sam, who's story we'll be following throughout the programme.

J Barton: One of the biggest problems, and often if you talk to people that suffer pain, chronic pain, is being believed in the first place. When Sam first became ill he was misdiagnosed, what Sam had wrong with his leg is very rare, so I can forgive people not getting it right, but I can't forgive them not understanding how much pain he was in. And they said he had lipomas in his leg and these shouldn't be giving pain. And they... people would say things like, 'Is he happy in school?' That was a good one...

S Barton: Yeah, I do remember one particular doctor actually suggesting, 'Do you perhaps think this is all in Sam's head?' And I found this all extremely distressing, due to the amount of pain I was in, that someone was essentially saying, 'Is he happy in school? Perhaps, is he making this up?', you know, and even if it was, for example, it doesn't change the fact that it was still painful.

J Barton: Once he had a proper diagnosis, once he saw the right people and they did the right scans and they diagnosed what was wrong with him and they could see what was causing the problem, then, obviously then he was believed. But I think for many people that are in chronic pain not being believed is one of the hardest things.

Kelloway: Sam Barton's story is of course unique to him, but there are issues and experiences that affect all of us who live with pain. On *Airing Pain* we want to be led by you and several listeners have contacted us with comments and questions that also have relevance to Sam's story. In the last edition we look at the complex subject of neuropathic pain and one listener, who responded to that programme on our Facebook page, the writer says, 'I have neuropathic pain, so the programme was especially useful', then goes on to say, 'I had two hernia repairs between the ages of three and five and when I was 38 I developed neuropathic pain in my groin.'

Another correspondent writes, via our message-board, 'My husband lives with chronic pain, and his doctors are not giving him, or me, any psychological help with dealing with the effects of the pain. When I suggested to my husband that he might be depressed and could maybe benefit from some pain management, he says there's nothing they can do for him and he has his own ways of dealing with it. I now feel that we can't discuss any of this without getting upset or arguing, which makes his pain worse, and makes me feel worse.'

A few months ago I went to see the counsellor at my local carers association, but I felt I didn't get on well with the counsellor and I don't want to see her again. Where else can I get support for myself and how else can I support my husband?'

Well you'll hear a lot about this subject, not just in this programme, but in future editions of *Airing Pain*. Addressing this questioner today is Amanda Williams, who is a consultant clinical psychologist in the pain management centre of the National Hospital for Neurology and Neurosurgery in London.

Amanda Williams: This is really rather moving and actually very typical of what happens, that pain doesn't just affect the person with pain, that it affects those who are close to them and care about them. It's not uncommon for people with chronic pain to feel that they're

managing well, because it sounds, when one suggests the pain clinic or help with pain management, as if one is saying they're coping badly, or they're not, you know, in some ways they're weak or they're failing.

But pain is incredibly difficult to deal with and while her husband may be right, that there's nothing that can be done and his own ways of dealing with this are the best, it's pretty unlikely and there's usually something to be learned from discussing this with specialists of pain clinics. And also very often with other patients who are at pain clinics, because many of these things take place in group settings where people learn from one another and offer one another ways of understanding pain that then all can benefit from.

But probably, if her husband did go to a pain clinic, then her involvement in helping him work on new ways of doing things, experimenting with different ways of doing things, would be best, so she can actually be a really effective asset for him in trying to do things differently. And many pain clinics really welcome husbands and wives and other, you know, close relations who are keen to help and support.

J Barton: People underestimate the effect it will have on a family group – it doesn't just affect the person that's in chronic pain, it affects the siblings, it affects the parents... When Sam was first on the medication and he was about 13, when we'd come back from London and been told, 'Well there you go guys – he's on the meds, off you go, get on with it.' Yeah? Unfortunately, the combination of the drugs, we hadn't realised that Sam was starting to hallucinate and see things.

So it all came to a head one morning when Sam and his little brother were sitting upstairs in bed and Sam was seeing things and he started screaming and he was having florid visual hallucinations. And unfortunately his little brother was sitting next to him when it happened and he was quite traumatised by this and the fact that then Sam was seeing things walking round the house. We'd go to sit on a chair and Sam would say, 'Don't sit there because, there's... Marvin's there.' The way Sam dealt with it was that he invented a goodie [**S Barton:** Yeah.] called Marvin. Now Marvin would chase away all the bad shadow people, weren't they shadow people?

S Barton: Yeah, I mean at the age of 13, you know, when you start seeing shadows step out of the wall... I mean it was really bizarre, it was really strange and it was really scary at the same time.

J Barton: However his little brother had even less insight as he was only ten and was absolutely traumatised by all of this and as an example of how it then affected the family

group, for six months afterwards he would not go anywhere in the house on his own. So we had some help from an organisation in Swansea called the Tristan Lewis Trust and they had a play therapist who started to see Robert and did the trick – after a while he did recover from the experience, but it took a good six months before he got over that at the age of ten.

Kelloway: This is *Airing Pain*, with me Lionel Kelloway. Another questioner to our message-board has touched on issues raised in this programme. But before we continue, please bear in mind that whilst we believe the information and opinions on *Airing Pain* are accurate, 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 and your circumstances and therefore the appropriate action to take on your behalf.

Now back to that question: ‘How can a psychologist help with pain management?’ Addressing your questions today is Consultant Clinical Psychologist Amanda Williams.

Williams: Well pain is very stressful, as several others have pointed out on your programme, and there are many problems that having pain causes somebody. So psychologists try to help address those. Some of the problems are outside the individual’s control, but there are still ways that people can protect themselves from things that are outside their control. But others have possibilities of control, for instance, we all have habits in the way we think and the way we react emotionally to problems and we characteristically do things in certain ways and that feels normal and usual and sensible and so on. And that works for most problems in our lives, and then certain problems, like pain, can challenge those because they don’t give way as problems to those kind of solutions that we’re used to using.

So a psychologist will try to help look at things from a broader perspective and discuss different ways of thinking about problems, different ways of reacting emotionally to them and different ways of handling them. Then those possible solutions are tried out and discussed. A psychologist really tries to work with people in a joint way, so it’s a shared journey of exploration, finding out more about what works for the person with the problems in their particular circumstances. There aren’t any answers that work for everybody but psychology is enough of a science that there’s some things that we can be fairly sure about.

Kelloway: Amanda Williams there.

So, bearing in mind Sam's story, what is the psychologist's role in a case involving a child or adolescent? Tonya Palermo is a paediatric psychologist and associate professor at Oregon Health and Science University in America.

Tonya Palermo: Chronic pain is actually quite common in children and adolescents and in large community-based studies there have been findings of 20-40 per cent of youth having some pain that persists over a three-month period. And among those youth those that have severe and disabling pain is approximately 5-10 per cent, which is almost exactly the same as the adult population.

Typically when we see youths for psychological treatment for chronic pain we develop some shared goals and those are around functional goals for the child. These may involve aspects of physical activities that they are no longer able to perform that they want to get back to, such as being on the basketball team again; these may be very practical, routine life activities, such as participating in chores around the house again; or these may be mandatory type goals, such as requiring some type of school attendance or participation.

And so we typically encourage youths to come up with a variety of goals that are beyond pain relief, because the focus on only pain relief can sometimes be counter therapeutic, because youth may not see the value in engaging in a variety of other activities, but want to focus instead just on controlling their pain – and we know that those approaches don't work as well.

S Barton: My goals were basically, I just wanted to work, wanted to get a job, wanted to be normal, go out drinking, doing everything that, you know, a normal 16, 17 year old would be doing. But it was almost living a sort of double life in a way, because when I was in a sort of remission, you know, when the leg wasn't hurting too bad, maybe for a couple of weeks, I'd be able to go out, go down the pub, hang out with my friends and then I would end up in absolute agony again, so I would kind of disappear off the scene completely, because I wouldn't obviously be able to go out, wouldn't be able to do what I wanted to do.

And I'd find it very difficult with work – because I was desperate to work – and I find it very difficult with employers, you know, to explain to them, 'Look, you know, this is why I've been off work today.' They knew, obviously, I had a problem, they would try and do their best to help me out and provide me with some work and I just got sick of letting them down all the time really, so I think that was the point where I decided that it would probably be best to apply for disability living allowance and income support.

Palermo: The way we typically explain to children and adolescents that activity participation may lead to pain reduction is that the temporal ordering of that, is that once you participate in activities, that that alone, both the routine involvement of that as well as showing yourself and feeling more confident in your abilities to do important things in your life, that that often leads to pain reduction. And so sometimes we don't need to think about a specific strategy to control pain, but we just need to instead focus on how to get back into important life activities and that that involvement will often lead to a decrease in pain.

Kelloway: Paediatric Psychologist Tonya Palermo and Sam Barton. I'm Lionel Kelloway and you're listening to *Airing Pain*.

One of the routes offered to Sam Barton was to undergo a three week residential pain management programme at the Bath Pain Clinic. His mother was also encouraged to attend with him, but how did her rather cynical and battle-worn teenager and his mum, get on?

S Barton: They did all this stuff, like, you know, guided meditation, which is just a load of... I don't really [laugh] believe in that kind of stuff, if you see what I mean. But it was very helpful being in a situation with people, obviously who are experiencing the experiences that I was going through at the time, you know, and it was a... sort of lifted me up a bit, you know?

They were trying to work us into a better routine, obviously. I was very sleep inverted, so I was not sleeping in the night, sleeping through the day, you know, which was the same as everybody else who was there, really, you know. And it was just a case of making us get up in the morning, making us do some exercise, whether it was painful or not, you know.

J Barton: I think being on the residential course in the pain clinic at Bath with Sam was really helpful, because I was able to speak to other parents in a similar situation. I would be able (to be) taught ways to manage this. When you do a course like that they ask you what is your aim from the course and mine was just to try and find a way to help Samuel, I think that was my goal. I didn't actually believe when I went on it that we could, so that's another thing I guess I gained from it, that we did find ways of helping him and it's simply being with other people and working together and being taught ways to manage it – it was very helpful.

Kelloway: Jan and Sam Barton there. And *Airing Pain* will be visiting the Bath Pain Clinic in a future edition. Another tool in the psychologist's toolbox is hypnosis. And there is evidence to show that it can be particularly effective for children undergoing painful medical procedures. Research into its efficacy is being carried out by Christina Liossi, who is a senior lecturer in health psychology at the University of Southampton and a clinical psychologist at Great Ormond Street's chronic pain clinic.

Christina Liossi: One of the benefits of hypnosis is that children can learn hypnosis very easily, it doesn't have any side effects and also techniques such as hypnosis can be generalised to other distressing situations the children find themselves into. So, for example, when I was working in oncology we were teaching children to use hypnosis for pain management for lumbar punctures or veni punctures. But then they could use exactly the same skills for nausea and vomiting management, for insomnia, for other distressing symptoms that they had because of cancer.

I am using hypnosis for my chronic pain patients and I have found it equally effective as in the acute pain setting. Although, I have to say that there are differences between acute and chronic pain, so it's not exactly the same situation.

The results have been very encouraging and very good in the adult population as well. For example, it has been used for woman with breast cancer that they have to undergo biopsies, for people that have to undergo bone marrow transplantation. But there is a small percentage of people that have low hypnotic ability, but even these people, even if they don't get the full benefit of hypnosis they get some benefit from the relaxation that accompanies hypnosis.

I think, that one of the things that really has stuck into my mind, was a five-year-old boy that I had taught him hypnosis, he had his lumbar puncture without any other medication just with local anaesthetic plus hypnosis, he was very happy about it. And then when I went back to the hospital a week later, I found out, that he himself had taught another little boy how to use hypnosis, because he was going to go for a procedure this other boy and was very scared. So he had taught him how to hypnotise himself – and the other boy went in to the treatment room, had the procedure and was very calm and very confident and there were no problems.

And, of course, you know, the parents were talking about it, and they said, 'What's going on? Who is this little boy who is teaching my son hypnosis?' That shows that hypnosis is something that can be beneficial and also easily taught even by a five-year-old to another seven-year-old.

Kelloway: That's Christina Liossi. You are listening to *Airing Pain* with me, Lionel Kelloway. So, back to Sam Barton's story, here's his mum, Jan:

J Barton: We had a few quite unpleasant years between about the age of eighteen and twenty one when it was difficult to for him to work, he was in pain again. So he had two options he was facing: do something or live like this for the rest of your life.

Doing something was risky, there was a big risk of making things even worse, if that were possible. So he was referred for what they call, a treatment called... which is a sclerosing treatment, which is a bit like what they do to varicose veins but a bit more sophisticated than that. And they inject the lesion, the vascular lesion, with the fluid with the idea to shrink it, and that's what they did.

The first treatment went okay, the second treatment was okay at the time, but he came back, and he was... and then blue-lighted into Morriston [Hospital, Swansea] a day later and he was in absolute agony. I have never ever got over that, ever got over... watching... listening to that. Will never get over, watching him screaming in agony, 'Please kill me.' I don't think I'll ever get over that.

S Barton: Punching myself on my head, trying to knock myself out.

J Barton: Oh, I didn't know what you were doing [laughter]. It was just one of the most appalling things I've ever witnessed. [**S Barton:** It was really, really painful.] And that's after working for seven years in intensive care.

S Barton: So it was one of those moments where you're in so much pain when you, literally, it's like you've switched off, you go inside your own head. And it's like nothing outside yourself is happening because of what's happening to you at the time. I have never ever felt anything like that before in my life.

J Barton: What did you say? It felt like somebody had stuck a blender in his leg, back of his leg and turned it on.

Palermo: Adolescence is a time of change in many areas for youth – both their cognitive development, their physical development and social relationships change dramatically. This can have impact on how parents and youth interact. And when you put that in the context of any chronic health condition, such as having chronic pain, there may be difficulties in how youth and their parents communicate about the child's pain and their management decisions. We have seen this in ways that we try to encourage parents to consider the level of decision-making power they give the adolescent. Because often this is very motivating when a young person is given their appropriate decision making capacity again instead of having the parents make decisions for them.

J Barton: We went to London and the surgeon we saw was excellent and said that he thought it probably wouldn't make things worse – there was a 10% chance that he might have some improvement and there was a chance that he could have a lot, a big improvement. And Sam, he decided to take the risk, didn't you Sam?

S Barton: If I didn't have the surgery and I'd continued down the road that I was going, to be honest, I was probably going to end up drinking myself to death or doing myself a nasty, if you see what I mean, you know? And I got to the point where I even said, 'Look, amputate the leg, if it's gonna help, just take the leg off', you know?

J Barton: We actually asked the surgeon...

S Barton: I really got...I didn't care, you know, I'd rather have lost the leg than continue. After years of being told, you know, 'Well one day this is going to get better. We'll find something to do about this.' I was told, 'This is it now – this is how you're going to be, you're going to have to put up with this for the rest of your life.' And that was a destroying moment for me.

Kelloway: A destroying moment indeed. And Sam's decision to undergo life threatening surgery?

J Barton: It all went extremely well. They removed part of the lesion, he didn't bleed to death on the table. Which was always a plus, wasn't it Sam?

S Barton: Yeah, yeah...

J Barton: And they were able to move some cysts inside the nerve sheath in his leg.

S Barton: And it doesn't hurt, I have no pain, which is miraculous really. I am completely pain free, you know, I was not even expecting that before I went in for the surgery, you know. If anything, I didn't go into the surgery confident that I was going to be better afterwards. I thought I it might be a bit better, maybe it might be the same, but it's worth trying it and this is brilliant, yeah – this is fantastic. Before I would not be able to walk, maybe even like a quarter of a mile without ending up in absolute agony for days and days on end and yesterday I walked for about three and a half miles with the dog [laugh], and obviously I've got a job and I'm going to work later on.

I can live a normal life without actually trying to live a normal life. I can go mountain biking, I can go surfing, I can start skating again, which means a huge amount to me, I mean it's essentially saved my life, you know, in more than one way.

Kelloway: Our thanks to Sam and Jan Barton for sharing that very moving story with us.

And don't forget that ***Airing Pain*** is here to help you, so if you'd like to put a question to our panel of experts, or just make a comment about the programme then please do via our blog, message board, email, Facebook, Twitter.

All this information is on our website, www.painconcern.org.uk. It's a one stop resource to get further information about this programme, including a glossary of medical terms used, and to download this and previous editions of *Airing Pain* along with a host of information on how to manage your pain.

In the next programme we will be exploring the subject of nutrition, weight control for those with lower back pain and mindfulness. But for now, I'll leave you with some personal advice from Jan and Sam Barton.

J Barton: A lot of people find it particularly helpful to try and make contact with other people in a similar situation, via organisations like Contact a Family or the various pain charities. I think it's quite useful to be able to contact and talk to other people and find what is out there in the way of advice.

Be careful what you read on the internet – don't believe everything you read online. However, there is useful information out there, and there is good, reliable, safe information out there, but do be careful that you don't believe in everything you read on the internet – just look for the help that's out there and don't give up.

S Barton: I would say to people that, no matter how hard it gets, just to keep going, keep pushing on and don't let it get you too down. No matter how hard it gets, and you will have those moments, where you hit rock bottom and you think nothing can ever go right, you know, and that this is it, game over. No matter how hard it gets, everything you do in your life, everything you say, everyone you meet – it defines who you are. It builds the character that you become and going through something as hard as I have been through, it has really turned me into quite a good person, you know. I've got a fairly strong character, I've got a fairly strong drive to continue my life and even if I was still in pain, still everything I was doing would still be defining who I am. So don't give up and just remember that you are a stronger person than most people would be.

Contributors

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