

## ***Airing Pain Programme 10: Young People in Pain***

***Patients and health professionals at a residential pain management programme in Bath talk about the pain management needs of younger people and the aims of the programme.***

*Paul Evans visits the Centre for Pain Services at the Royal National Hospital for Rheumatic Diseases at Bath to find out about the pain management programme there. Clinical Director Dr Lance McCracken explains how the programme helps people get on with their lives and we meet the patient group to learn about their experiences in living with pain, what brought them to Bath and the things they've learned during their time on the programme. We also hear about how the team at Bath provide specific services to younger people and how pain affects their families and sleeping habits.*

**Paul Evans:** Hello and welcome to ***Airing Pain***, a programme brought to you by Pain Concern, a UK charity that provides information and support for those of us who live with pain. Pain Concern was awarded First Prize in the 2009 NAP awards in Chronic Pain and with additional funding from the Big Lottery Fund's Awards for All programme and a voluntary action funded community chest, this has enabled us to make these programmes.

**Sandra:** I'm Sandra. I'm from Bristol, and I've come here to try and see if they can help me with my pain.

**Anne:** I'm Anne. I'm from South-West Wales, I've been in pain since 1998 and I just want to get some mobility back, as well as getting rid of some of the pain.

**Jenny:** I'm Jenny. I've been in chronic pain since 2001 and I'm here to get some tools and a way I can manage my pain, and mobility and strength in my muscles and things like that.

**Alan:** I'm Alan. I've come down from Scotland to try and get my pain back under control, as recently it has escaped.

**Jan Barton:** Sam eventually went to a project in Bath for adolescents in chronic pain. It was an excellent project. They said: 'we won't cure your pain, but we can teach you how to deal with it.'

**Evans:** I'm Paul Evans and each fortnight on ***Airing Pain*** we look at the topics that affect those of us who live with chronic pain: the coping mechanisms, medical interventions and therapies that might help us to regain control of our lives. But first, our usual word 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 wellbeing. He or she is the only person who knows you and your circumstances and therefore the appropriate action to take on your behalf.

Today we're focusing on the Centre for Pain Services at the Royal National Hospital for Rheumatic Diseases at Bath. It's a national, highly specialist service for treating young people and adults who have been to other pain services but have continuing problems. The courses are usually run on a residential basis and its clinical director is consultant clinical psychologist Dr Lance McCracken.

**Dr Lance McCracken:** Most of the cases we see defy easy categorization, in other words, they – a lot of cases have somewhat complex diagnostic situations, they're having a hard time getting a single consensually agreed-upon diagnosis. Having said that, we see a lot of people with generalized pain problems, not just affecting one part of their body – it may have started in one part of their body, but then it affects other parts. People who've had back injuries and who've had surgery for that and who haven't done well. Patients with generalized muscular skeletal pain or with fibromyalgia, post-lumbar surgery pain, are probably some of our biggest groups.

A pretty decent fraction of people we see are patients who have had little obvious precipitating circumstances, like they just sort of... pain came on without a particular accident or illness and so that's maybe 20% or a fifth of the people we see have just chronic, very disabling pain but without a clear reason.

A difficult pain problem can happen to almost anybody. The main criteria for us is that if pain is having a very large impact on people's lives, socially, and with their physical activities, and emotionally, with their sleep patterns, so if the impact is large or significant, and if other treatment services haven't significantly helped, if people are still suffering. The largest patient group that we decide not to treat are people who are doing pretty well, meaning they have chronic pain but their functioning is ok.

**Alan:** I knew about this place and I suspect all the others that have researched pain and the various things that can be used to treat it and so on, knew of the existence of Bath. But I didn't actually choose to come here – that was a referral from my pain consultant, who said that this was a different approach and one that should be considered alongside all the standard physiotherapy and all the standard drugs, that we've all gone through one way or another.

**Evans:** You've all come from areas – South-West Wales, Bristol – not so far – Birmingham, Scotland... Was there nothing like this in your local area?

**Jenny:** Nothing at all. They do 'to be kind to yourself' kind of courses where they look at pacing and relaxation, but the difference with this kind of course is, you know you're not going to ease your pain. In fact, when you come here, your pain may even get a little bit worse, because obviously you're doing more what is called 'body conditioning' here. It's not so much physio, it's choosing exercises towards the values that you want in your life. And there's nothing like that in Birmingham, or anywhere nearer, so that's why the pain specialist did actually say that this is the best and only course in the UK that actually does such a programme.

**Alan:** One thing I will say just to stand up for Scotland is there is a similar course up there, but it's done on a day release basis down in Glasgow and that just wasn't the right attitude for me. I wanted to get it all done in one block.

**Anne:** I could say about my area in Wales. They have got Bronllys which is a residential course, but they don't have facilities for people that need the special beds and maybe some nursing input, so they... I was referred to Bronllys, but they referred me on to here.

**McCracken:** People come here out of desperation, a lot of times. People certainly come with the hope or wish for a cure, that's for sure. Some people come with a confused or confusing set of goals, because they, sort of... on the one hand they understand that we don't do a cure here and their doctor tells them that, yet on the other hand, they still want it. And we're quite straight from the beginning: we don't offer a cure, if what we mean by that is that the pain will go away. Patients have great results, but they don't get cures. Not for the most part.

**Evans:** You say, 'great results' – what is a 'great result'?

**McCracken:** I mean, in general, a great result would be... patients want to do things, people want to do things in their life and since their pain started, they're not doing those things anymore – they're spending their time trying to deal with the pain, instead of doing these other things. For us, a great result is making that shift back, away from wrestling with the pain and seeing another doctor, seeking a cure, spending all your time on that and back on to the kind of family life and social life, and work life and physical activities and the kind of complete life activities that they actually want to do, yeah, back on their goals and desires, not wrestling with the problem.

**Evans:** Dr Lance McCracken. Some residential courses at Bath Centre for Pain Services last for 3 weeks, but for patients like Sandra, Anne, Jenny, Alan, who are all less able-bodied,

the courses run for 4 weeks. And they stay within the hospital, rather than the residential flats. I spoke to them at the start of Week 3.

**Alan:** First of all, they get to know us. They have a standardisation to find out where we are to begin with, both in terms of measurements, attributes, the way we approach pain, so they know where we are. I presume, at the end of the 4 weeks, they'll do that again and see what the difference has been. And then we have a number of strands throughout the 4 weeks: one looking at body conditioning, which is looking at how we adapt to physiotherapy, in our... because when you're in a wheelchair, you can still do a standing exercise, which is a different approach than most physiotherapists get. That's one strand. And then we have the psychology strand...

**Anne:** We've got 3 psychologists, actually, covering the course.

**Evans:** And what do they do with you?

**Anne:** 'Mindfulness', it's called.

**Jenny:** You can't change your thoughts, but it's looking at how you can notice them, but still try and give yourself options. The pain's always going to be there, so it's trying to manage your life, so the pain's there... instead of relaxation, it's not a relaxation thing, it is more about being aware, isn't it, of our thoughts?

**Alan:** Yeah, so you don't go forward and back all the time, but you become aware of what's happening now. You don't analyse either, that is one of my big weaknesses.

**Jenny:** Yeah, I think it's all of us.

**Alan:** But you just observe, you know, what's going on.

**Evans:** One of the frequent questions Pain Concern gets on its message board is: 'What have psychologists got to do with pain?'

**McCracken:** It's a great question. It's important and very confusing and so important it's worth saying it as many times and in as many different ways as we can. Everyone comes into treatment and at one level they want the same thing: they want their life to be better. As human beings with pain, we quite naturally look at the problem as a pain problem and like: 'The pain is there, I used to function, the pain came, now I don't function. If I could get rid of the pain, my functioning would be good.'

That's how they understand the problem. It's completely natural – I'm not saying that's wrong, I would never say that that's wrong. There is something very naturally human about

encountering a pain problem like that. The difficulty with encountering a pain problem like that is that people's experience over 10, 15, 20, 30, 40 years is that the more they try to follow that, the more frustrating their life gets and the smaller their life gets. Nonetheless, the other goals are still there: 'I want to participate in my life with people I care about. And I want to finish school. I want to do meaningful work. I want to be a role-model for my children.' And notice: it's all behaviour. So what if psychologists had a technology to help that behaviour to happen?

**Alan:** A lot of us will want a reason for what's happening, so when we get some pain or whatever, we try to analyse why, was it because of this, that or the other, but that's taking you away from what's going on. You've got some pain now, at this particular moment, and you've got to work with it at that time.

**Evans:** So it's getting through the moment rather than the longer term.

**Jenny:** Yeah, not looking at... it's like our minds want to offer us a thought straight away and an action straight away, so it's trying to do something different from the norm. So it's not auto-pilot. So if we approach something that in our history – it may have been we've had a fall before, or something like that – it's about taking it at that moment, step by step, trying to notice that we've got those thoughts of anxiety or 'we can't do it', but trying to see our current ability, if we can manage to do that particular thing. So we do a thing called a 'check-in' and we do what's known as the 'hot cross bun' and that's we have to check in with our body sensations, our thoughts, our feelings and our actions. And then that gives us the options that – do we just go down the path of least resistance, or do we try and go towards what we value in life.

**McCracken:** Most of the treatment time for most of the patients we see is group-based. Now, we provide an array of different services. There are some services that we deliver that are exclusively individual-based from start to finish. We do a pretty small fraction of that. This is for people whose difficulties and circumstances would prevent them from participating in a group and doing well in a group. Most people are in groups – groups of between six and 10 people. Groups are good places to do treatment in some ways, because it's a social situation, it's like life: it includes dealing with other people, communicating with other people and dealing with their own emotions and experiences that happen around challenging social circumstances. So there's a bit of reality and there are challenges there that are very useful in treatments, so that's a – that's a good side of that.

**Evans:** How far into the programme are you?

**Sandra:** Midway, beginning of the third week.

**Evans:** So where are you all mentally in your change?

**Alan:** Well, I'm just still open. They've convinced me to carry on this thing for the next 10 days and that's what I'll do and try and use what I've learnt so far and what I will learn in the next 10 days.

**Evans:** Why did they have to convince you?

**Alan:** Because that's my weakness, in that I have to be convinced of something to be able to carry on giving it its due and being able to say, 'yes, you've earned the right for me to carry on listening'. Hopefully, I'll begin to live more in the moment, begin to choose things, rather than decide, which is one of the benefits of this course.

**Jenny:** I can only say for myself that I have noticed changes – that I am really recognising thoughts and how they are holding me back a lot of the time, you know, my feelings. And I may have noticed them before, but I didn't really know how to deal with them and also they used to stop me from doing quite a lot of things, whereas now I'm a little bit more proactive in doing certain things in my life. Not pushing them aside – no, recognizing they're there – but I can still move forward. So, me personally, I've noticed that I've... I have had some changes in the way I do think.

**Evans:** Do you think you will be able to take that out into the real world, beyond the hospital walls?

**Jenny:** It'll be difficult. It's going to be difficult. You know, we have weekend leaves, we've just all had a long weekend and you do come across a lot of challenges and I think a lot of it's down to communication as well, isn't it?

**Alan:** Yeah, one of the things I think will help us is – those of us that will be able to take advantage of it – is that one day a week – it's turned out nearly, or one day a fortnight – partners and family come in and sit in on it. And not only does that show them what's happening, but it gets them involved, so they'll be able to work with us afterwards to transfer it to the real world.

**Evans:** How the team prepares them to re-enter the real world is something we'll deal with later in the programme. But we've already said that the Centre for Pain Services in Bath treats people of all ages, which includes children down to the age of 11 and sometimes even younger. Dr Hannah Connel leads the team of physios, occupational therapists, doctors and nurses who all provide this service to help young people with chronic pain get back to age-

appropriate activities. You will also be hearing the voices of Sam Barton and his mother Jan, who you may remember from an earlier edition of *Airing Pain*. Both attended the course when Sam was a teenager. So, age-appropriate activities?

**Dr Hannah Connel:** What we mean by age-appropriate activity is anything that you would expect a young person or an adult of that age to be doing. So for somebody who's 11 to 18, most young people are in education, so it's helping people with pain access education. For an adult, it might be work or it might be participating fully in a family life.

**Evans:** I've talked to somebody who had been on this programme. He was a teenager when he came. He said, 'drinking, going out with my mates, going to school and all that stuff', and that's what I associate with a normal teenager.

**Sam Barton:** I just wanted to work, wanted to get a job, wanted to be normal, wanted to go out drinking, doing everything that, you know, a normal 16-17 year-old would be doing...

**Connel:** And that's exactly what we would hope young people would be getting back to doing, so in one of our young adult programmes for 18s through to 20s, we expect them to do that. And the team consider it a very good outcome if they've been and had a really good night out, because that's what their age group should be doing, so that's age-appropriate activity by my book too. Many services – some in this country, but quite a few abroad – will take the children away and admit them and treat them more individually. We would rather treat the parents and the child as a dyad, because basically the parents are there – once they get home they're present 24/7 – whereas we're not. So if we can get the parents to manage things differently, then the outcome's overall much, much better.

**Evans:** But is there a bigger point here that pain doesn't just affect the individual, it is, well, a family thing?

**Connel:** Yeah, absolutely, and there's some really lovely research that one of my colleagues did a few years ago looking at the impact of a child's pain on the parents and the parents were describing things like feeling completely hopeless, feeling accused of causing the problems, you know, just stress levels are very, very high. So it undoubtedly affects the parents.

I think you need to remember that it affects grandparents and extended family and also brothers and sisters. So for example if you've got a sibling that can't travel in a car, that has huge impact on what the family can do as family-shared activities, holidays, all sorts of things. Parents may have to give up work to look after the child with pain, which has a huge impact on the finances of the family.

**Jan Barton:** When Sam was first on all the medication, and he was about 13, when we'd come back from London and we'd been told: 'Well, there you go guys, he's on the meds, 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 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 he... when it happened and he was quite traumatised by this and the fact that then Sam was seeing things walking round the house and we'd go to sit on a chair and Sam would say: 'Don't sit there, because there's – Marvin's there.' Because the way Sam dealt with it was that he invented a goodie called Marvin. Now Marvin would chase away all the bad shadow people, weren't they? Shadow people?

**Sam:** Yeah, you know, at the age of 13, 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.

**Jan:** However, his little brother had even less insight as he was only 10 and was absolutely traumatised by all of this. And as an example of how it then affected the family group, for 6 months afterwards, he would not go anywhere in the house on his own.

**Connel:** So our approach here is: yes, the child has the pain, but the impact that the pain has is on the family as a whole and that's what we'd like to treat.

**Evans:** Parents aren't just observers, then?

**Connel:** No, no – parents here in Bath are certainly not observers. As part of the assessment process, parents have to consent to taking part in the programme fully. There's an element of the programme that looks at parenting and we try to enhance some parenting skills that we've learnt that are helpful for parents who are struggling to manage a child with chronic pain. The parents also need some looking after as well, because they get very, very distressed, so they need some skills and an approach to managing their own distress and living the life they want to do for themselves, rather than the whole family focus being just on the child. And once that can open up a little bit, parents and children find some pretty different ways forwards and some ways of doing some of the things that they've lost along the way.

**Evans:** Describe some of the parenting skills that you might try and give people.



**Connel:** Well, I guess it's less certain parenting skills, although sometimes those do need to be looked at, sort of, you know, praising up good behaviour, managing sort of, tantrums and thinking about how to manage, sort of, difficult situations, managing the return to school, how to talk to teachers, how to get the educational support that is needed. But we aim as well to help parents look more flexibly at the situations that they're in; to think about how their child's pain affects them; think about how their thoughts and their emotions and their distress might lead them to react or lead them to act in certain situations that in the long term aren't particularly helpful. A great example of that is when children are in excruciating pain at night and you feel very alone and you feel very, very scared – a lot of parents will have the experience of having taken their child to A&E and most people would report that that probably wasn't the best course of action. So what we aim to do is help the parents understand where *they're* at, so that they can make choices and they can do things that in the longer term help them and serve them better.

**Evans:** Because parenting a teenager who is not in pain is not always the easiest thing in the world, is it?

**Connel:** No, parenting teenagers is not easy at all and I think when you've got a teenager who's in pain, you've got the ordinary teenage issues and the pain issues on top and the parents often say: 'I'm not sure what's pain and what is just the child being the age that they are.'

And we give parents, I guess, here, an opportunity to think that through, so that they can try to manage difficult situations, holding both those ideas in their heads and making the best possible decision they can. I think one of the things that a lot of parents do is, because they feel sorry for their child in pain, is they let them away with things, which is very, very understandable, but sometimes doesn't help in the long term.

And a great example of that would be: if you've got a child who has been up all night, hasn't slept well, is feeling ghastly, letting them sleep in and having breakfast in bed. Now that's a lovely parenting thing to do, and certainly, in certain situations, I would encourage it completely. But if that becomes what you do *most days*, then you haven't got a young person who's getting up, who's doing things for themselves, or is in a place ready to go to school.

**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 of trying to manage this. When you do a course like that, they ask you: 'What is your aim for 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 that – 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 in managing, it was very helpful.

**Barton:** 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 – it 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.

**Evans:** Staying with the parenting business, sleep and teenagers go hand in hand. With the best will in the world, it can be difficult to get a teenager out of bed.

**Connel:** Absolutely.

**Evans:** So how do you change a sleep pattern?

**Connel:** First of all, I think we need to remember that teenagers go through developmental bursts, when they sleep an awful lot. And they need to have extra hours in bed. When you have pain, it's very tempting to sleep more because you're not so aware of the pain, to sleep more because you haven't got other things that you can do anymore and also there's the quality of sleep that's really poor and disturbed, so young people often spend a lot of time in bed, but not actually sleeping well.

What we would look at is if the sleep is getting in the way of young people being up and active in what I would call the 'active hours', so Monday to Friday, between about 9 and 4, so roughly the school plans, it needs to be looked at. If young people need to sleep in at the weekend, then that's what they do.

In the early days of turning round a very disturbed sleep pattern, you need to keep the consistency over the weekends. So you need to have a sleep pattern where young people are going to bed at an appropriate time, but more importantly getting *up* at a regular time, whether they've been to sleep or not. It's a bit more of a jetlag approach. Young people feel really quite awful in the first few days, but the sleep changes happen quicker.

I think when we've tried to do this more gradually, more gently – so going to bed an hour earlier, getting up a little bit earlier – young people feel horrible, but for even longer. So we would rather do it quite quickly. And I think it's that those times where young people need to be getting up at weekends and not having a lie-in.

But once their sleep pattern has improved overall, then they can go back to a more age-appropriate, long-lines sleep pattern at the weekends only, as long as they're up for school or whatever activity that they want to do in the week.

**Barton:** And it was just a case of, you know, making us get up in the morning, making us do some exercise, whether it was painful or not, you know, and just trying to get us into a better routine, you know.

**Evans:** I've heard the teenagers here use the term 'boot camp'?

**Connel:** No, not really, um, I think it could sound like that because there is a clear programme that they're expected to participate in. But I think the approach here and hopefully the kindness and the insight of the staff would mean that the experience that they have when they're here sends that term away. Because I think 'boot camp' means to me, sort of, pushing somebody to do something, forcing them to do something and that's certainly not what we want – we want young people to work out what works for them and choose to do it because the outcome for them is what they want.

**Evans:** It's a 3-week programme. Can you see the changes in personality as they go through it?

**Connel:** Oh, we see some dramatic changes in young people. When young people first come in, the first couple of days of the programme, they're very, very quiet, they hardly talk to each other or the staff and the parents have to do a valiant attempt to keep the conversation going. As the first week goes on, the young people sort of... you get to know a little bit more who they are and what they're like and you start learning about them and they learn about us as a team as well and we start getting to know each other and getting along.

The middle week, the parents are not present for many sessions, and it's at that time that the young people really do come out of themselves and we get a lot of fun, we get their own choice of music coming in, they make friendships within the group and have quite a nice time, even though they are working very, very hard and addressing some difficult material. And I think in the third week, you begin to see the young people separate a little bit from the clinical team and start thinking about going home and then you can get much more of a sense of who that person really is, what they're going to do when they get home and the sort of life that they really want to be leading.

It's not uncommon for young people to change their hair, or change their clothes, or look quite different as they leave the programme. So we've got the physical gain, so that they're often fitter and walking better, but that's often enhanced by a change of hair-do, make-up

being put on, different clothes, something like that as well. So it's a lovely change that we see over the 3 weeks and it's even better at the 3-month follow-up – they're even more different there.

**Evans:** How do you prepare people for going to the outside, if you like, after the 3 weeks?

**Connel:** Okay, the last week of the programme really is focused on that. There are sessions where young people work out their timetables with school, think about how they are going to fit exercise in, think about what... which friends they are going to contact, think about which healthcare professionals are going to be useful to them in the future. So the whole of the last week is thinking about what you've gained in Bath and how you're going to take it home and make it part of your life for the long term.

**Evans:** Dr Hannah Connel. And that's the end of this edition of *Airing Pain*. If you or someone you know has benefited from these programmes and would like them to continue, then please consider making a donation to secure *Airing Pain*'s future. It's very easy to do: just go to our website at [painconcern.org.uk](http://painconcern.org.uk), where you'll find a 'Make Donation' button. You can also download all the past editions from there and if you'd like to put a question to our panel of experts or just make a comment about the programme, then please do so via our blog, message board, e-mail, Facebook, Twitter or even pen and paper, in which case you'll need our address which is: Pain Concern, 1 Civic Square, Tranent, EH33 1LH. And I'll leave you with some final thoughts from the patients at the Centre for Pain Services at Bath.

So, a question to all of you – half-way through the programme, are you glad you came?

**Anne:** Oh, absolutely.

**Sandra:** Yeah, absolutely.

**Jenny:** Yeah, you know, best thing that's ever happened.

**Alan:** I hope I am. But again, that's down to me, not the course – it's opening my eyes up, and it's – it'll be how it gets used when we leave here.

**Anne, Sandra:** Yeah.

**Alan:** And I'll be able to answer that question when we come back for a review session, once we've had 3 months or whatever, of using it. As you yourself said, would we be able to apply it in the real world? That's the critical answer. And if it's yes, then it's a really good course.

## Contributors

- Bath Patient Group
- Dr Lance McCracken, Clinical Director, Centre for Pain Services at the Royal National Hospital for Rheumatic Diseases, Bath
- Dr Hannah Connel, Chronic Pain Service Lead
- Sam Barton
- Jan Barton

## Contact

Pain Concern, Unit 1-3, 62-66 Newcraighall Road,  
Edinburgh, EH15 3HS

Telephone: 0131 669 5951

Email: [info@painconcern.org.uk](mailto:info@painconcern.org.uk)

**Helpline:** 0300 123 0789

Open from 10am-4pm on weekdays.

Email: [helpline@painconcern.org.uk](mailto:helpline@painconcern.org.uk)

To make a suggestion for a topic to be covered in ***Airing Pain***, email [suggestions@painconcern.org.uk](mailto:suggestions@painconcern.org.uk)

Follow us:

[facebook.com/painconcern](https://facebook.com/painconcern)

[twitter.com/PainConcern](https://twitter.com/PainConcern)

[youtube.com/painconcern](https://youtube.com/painconcern)