

Airing Pain 118: Pain Management in Young People

How chronic pain in adolescence requires different pain management strategies.

*In this edition of **Airing Pain**, Paul Evans looks at the issues concerning pain amongst adolescents, including the impact on parents. First-off, Paul speaks to Dr Jeremy Gauntlet-Gilbert, principal clinical psychologist at the Bath Centre for Pain Services, to talk about the “end of the road” residential pain management programme the Centre has for young people from across the UK who have not had success at other institutions.*

Paul also speaks to Amyra and Taylor, who have first-hand experience of the programme, about their time in Bath. They also discuss how chronic pain has affected their personal lives, including their performance at school and in exams.

The parents’ experience is also explored as Paul speaks to Taylor’s mum Sandra McCann and Louise Bailey, the mother of another patient. They describe how the Bath Centre for Pain Management has made a positive impact on the ability of their children to have a more regular life. Paul also discusses with Louise and Dr Gauntlet-Gilbert about the wider impact on siblings and the rest of the family.

Dr Gauntlet-Gilbert also talks about the Centre’s commitment to transitional support for individuals between adolescence and adulthood as well as beyond. This edition concludes with the parents and young people delivering their verdict on the Bath Centre for Pain Services’ programme. One that indicates it is a very hard but rewarding process, with the young people clearly finding enjoyment in their time there.

Issues covered in this programme include: Children and young people, CRPS: complex regional pain syndrome, development, education, family, flare-up, friends, homeschooling, hypersensitivity, independence, mindfulness, pacing, physiotherapy, residential programme, school and stomach pain.

Paul Evans: This is **Airing Pain**, a programme brought to you by Pain Concern, the UK charity that provides information and support for those of us living with pain and those who care for us. I'm Paul Evans.

Amyra: I did not realise how awful I can be on one of my bad days. Honestly, it was weird because I had two people playing me. I didn't realise how I actually am on my bad days

Louise Bailey: They were shouting in the morning to say, 'Come on, you got to get out of bed' [but], I can't get out of bed, I haven't slept, I can't move my arms, etc. And then it's the crying – it's affected the whole family.

Evans: Adolescence, that transitional period from the onset of puberty, roughly from the age of eleven or twelve, is when children grow physically and mentally into adults. It can be a stressful time, not just for the young person going through it, but for parents and siblings. Now, throw chronic pain into the equation, and there's a whole new set of issues to deal with. The Bath Centre for Pain Services runs pain management programmes for people of all ages, including young people from the age of nine. They can attend a three week, group-based, residential pain management programme accompanied by their primary carer, who's usually a parent. It's a national service so people from all over the UK could be referred there. So obviously apart from helping young people manage the pain in their lives, why is it so important to deal with what are probably lifelong conditions so early in life? Dr Jeremy Gauntlett-Gilbert is Principal Clinical Psychologist at the Bath Centre for Pain Services.

Jeremy Gauntlett-Gilbert: If you can set things back on the right track in this terribly important developmental period, then you'll have done the right thing at the right time. You don't want to be doing this late. Some of the physical developmental changes and the mental developmental changes have become concreted in. And equally you feel the pressure of not wanting to miss opportunity, at fourteen, fifteen, thirteen, you're doing things with your peers at school, you're having independence experiences that are very hard to make up for later in life. You know, it's very hard to sort of claw that back. There are critical moments developmentally, obviously, physically if you want to think biologically, but truly in terms of the development of independence, and your ability to socialise with people. So, we do feel the pressure breathing down our neck as paediatric clinicians that we really need to get young people back on track at the right time. The good part is that at least there is a track to get back on to – school and education do provide a sort of natural developmental support, you know, they can get back into something and get back on it in a way that it's harder to as an adult.

Evans: Who do you see then?

Gilbert: We are in a funny service, it's a little bit like being, for example, at Great Ormond

Street, so we only see the people who have struggled to benefit anywhere else. So we're very much the end of the line, in a sense. So we see young people who been through paediatric services, have perhaps tried some local physiotherapy, tried some medications, there's usually a mix of experience, people have usually seen quite a few clinicians, a proportion of people feel slightly disappointed with what they've been through. By definition, it hasn't worked. Otherwise, they wouldn't have to come to us, would they? But also, you know, you know, as well as anybody that pain services are patchy across the country and patchier for children and young people. And sometimes people have had unfortunate messages given to them, something along the line of, 'Well it's all in your head and your parents shouldn't be so anxious and I really can't see why you've got this much pain, because your scans look fine.' Now this is the same in adolescent and adult conditions, only [in this case] you've got the kid and their parent responding to these sometimes slightly disappointing treatment experiences. So, we're trying to take people who've usually had pain for a long time, and missed a chunk of school as a rule. This is usually not their first rodeo in terms of treatment experiences, and we are trying to hopefully provide a level of intensity and specialism that can nonetheless move things on.

Evans: You're residential?

Gilbert: That's right. Yeah. So, children and their parents, or one parent come and stay with us for three weeks, so they can come from all over the UK. So they usually, as you can imagine, arrive fairly nervous and terrified into the group. And one of our measures of success is the amount of noise and rowdiness we can achieve by week three in the group of young people.

Evans: That's Dr Jeremy Gauntlett-Gilbert. Well, I joined the last day of one of the pain management programmes in Bath earlier this year. So, you can measure the *rowdiness* index at the end of this edition of ***Airing Pain***. Two of the young people I spoke to were Amyra and Taylor, Amyra first.

Amyra: I have chronic pain in my stomach. So, I have chronic stomach aches, controlling the pain has been difficult, and I've been quite withdrawn from life. So, Bath was the last resort to help me just get back on track and [I] thought it would be perfect for me.

Evans: Tell me something about your pain. I mean, how long has that been affecting your

life?

Amyra: Since February 2017. So, it's been about two and a half years.

Evans: How old are you then?

Amyra: Seventeen, turning eighteen soon.

Evans: Has it affected your social life, your education?

Amyra: I've not been in education in two and a half years, since I've had the pain, like proper education at hospital, home schooling. And social life is pretty limited, [I] don't have much of a social life.

Evans: Taylor, tell me something about your pain.

Taylor: So, I've got CRPS in my left foot. I've had it since September 2017. So, it's just coming up for two years since I've had it. It's been like a constant thing since I got it. Some people have breaks from the pain but I've just like had it full on, luckily mine hasn't spread though, because it can spread.

Evans: How has that affected your education?

Taylor: I've stayed in education, but I've like... my attendance isn't as great as it used to be. It is getting better now, but then obviously, you do get bad days where you just can't physically go in.

Evans: That's Taylor, now as we've heard she and each young person is accompanied by a parent, and parents are not there just as chaperones, but as participants. So, do they work separately from their children? Dr Jeremy Gauntlett-Gilbert.

Gilbert: It's a little bit of both. Most of the time we have them in with the kids. That doesn't mean that they're working with *their* child every microsecond of the time. Sometimes, although they might all be in the same room, we have parents working with parents and kids

working with kids, or parents working with other people's kids, which is quite an eye opening experience for the child and the parent. But of course, we give the parents a little bit of time to themselves because there are absolutely things which people will want to say and want to discuss and want to put out there, which they wouldn't say, right in front of their child. And it's really important that people have the space to do that.

Evans: Well, we heard earlier from Taylor and Sandra is her mum.

Sandra McCann: For the first week, we were in all the classes that the young adults were in as well. We sat through the activity, the physio, the psychology, the specialist kind of sessions that we had. We also partake in the physio side of things, body conditioning. And then the second week less so, we basically had free time which was amazing. And then [in] the third week, we were back in all the classes along with them. I think it gives you a better insight into what your own child is going through but then also what chronic pain entails for children at that age.

Evans: It seems very forward-thinking to bring mum or dad along as well. But I'm just thinking, is it always productive to have a parent there, or can a child, you know, be cloistered by his mum or dad?

Gilbert: That's a good question, I'd stick my neck out and say that it's always helpful to have a parent there. Now, obviously, you want parents to be co-therapists, we want them to look and see the skills and techniques [that] their child's learning. We want them to do the exercises, if it's a physio so that they can support that at home and do it alongside their kid. And as you point out, it's also the case that some parents have been so kicked about by having the experience of having a child in pain, not being able to help, not always getting the services that they would have wanted, that it's helpful for the parents to reflect on what they can do to help the child move forward. We don't really see parents as the problem, but we definitely see them as part of the solution. And so, if you do have a parent who is – it's a horrible phrase – overprotective. Anybody who's been a parent will be sympathetic to that one; it's not a critical term. Then having them there, [which helps] that parent to gain the confidence to step back, to be able to see that their child has more capacity than they feared up until that point, is a nerve wracking but really important and valuable piece of therapy.

Evans: It can be overlooked that pain affects every member of the family, not just the person

within pain, and the overbearing parent is not doing it out of spite.

Gilbert: Good Lord no.

Evans: It's because their lives are in turmoil as well.

Gilbert: Yes, the whole family is in turmoil. I think we're becoming increasingly aware of the less visible siblings, as well, who are trying to live their lives whilst a lot of parental energy and attention is diverted on to the to the young person who is unwell. And it's sad to say this is usually gendered, isn't it? It's usually mum who ends up having the burden of providing a lot of the emotional care and doing the heavy lifting in that area, and very often being the person who takes the young person to appointments, negotiates with consultants and physiotherapists and things like that. And I'm sure that's not quite how they envisaged their life panning out at this stage. So yeah, it's a *family* that takes the hit, not just the child.

McCann: It brings you closer with your child being here. Obviously, you've got your child in a one-to-one basis for three weeks. There's no distraction from work, or time pressures through anything else, so therefore, you're spending the time with them, you can see exactly what's happening with them. It gives you that insight that probably nobody else [has]. So, we'll head back up to Aberdeen today. However, Taylor and I know what's going on here, but like [to] communicate that three weeks back to the people that you live with the people that you're close to. It's going to be quite a struggle, I would imagine.

Evans: Are you helped with that here, of how to reintegrate with your own family?

McCann: Definitely, yeah, there was a lot of time spent yesterday especially going over the experiences that other people have had. And we did some role plays yesterday, which were very insightful too, I think, to both the adult and the child.

Evans: In what way?

McCann: Well, yesterday we were set up as a parent with somebody else's young person. And basically, that young person had to explain to you how they were feeling [and] how they dealt with things normally, then you had to act as that young person. And then they had to try and bring you out of where you were on your bad days, and let them have an insight into

how they acted and how it was perceived to other people, while at the same time allowing them to think what would actually help them going forward and how they could talk themselves out of just saying flat no to doing things or using the strategies that they've learnt here over the last three weeks.

Taylor: It's weird having someone else being you, you realise how difficult you can be on your really sore days. And even just explaining how, like to the other person how, what you would do and how you would react. It's weird, and it makes you realise what you're doing. So, I think like, you kind of feel a bit stupid, but then we had to try and talk the person who was playing us out of, like, 'Oh come on, let's go do something.' So it was weird. You realise how difficult you actually are.

Amyra: I did not realise how awful I can be on one of my bad days. Honestly, it was weird because I had two people playing me. I didn't realise how I actually am on my bad days. It's kind of a weird feeling because this [was] even explained [to me] before the role play. You don't really know how you act, even when you start explaining how you act. It doesn't seem nice to know how you act, but then it's kind of helpful because you realise okay maybe I'm quite angry, frustrated, quite nasty, snappy on my bad days.

Evans: So, people playing your character, how do they know all this?

Amyra: We have to tell them how we act and then they can also pick up on how we've been acting here. So, then they got some of the posture, some of the facial expressions and some of how we speak and we had to explain to them how we are. It was a bit uncomfortable because it's weird because you don't know how you act unless someone else does it for you, so it is like a mirror. That is mind blowing because you don't realise how you actually are on your bad days, what type of person you can be.

Evans: The other thing that occurs to me to do something like that. You're not the only people in the partnership if you like, having a role play – your parents have to role play as well. So, did you find out something about how your mother or her alter ego, the person playing your mother if you like, perceives you?

Amyra: I think I realised how difficult it is for my mum on my bad days to me, I've just realised how difficult I can be and how difficult it is when you know your loved one's in pain

and you're trying to just get them to do things and try to give suggestions, but I also think my mum has realised what it is like having pain and how we act.

Evans: Louise Bailey is mum to Jasmine who's had Complex Regional Pain Syndrome- CRPS- since she was ten.

Louise Bailey: With Complex Regional Pain Syndrome, she gets the sensitivity, so she couldn't wear clothes. It was coming to winter, so she couldn't wear long sleeves or if she could it would only be for a short amount of time. She missed a good 50% of her school and with it being a main GCSE year, obviously, it was a grave concern.

Evans: GCSE. So, she's fifteen now?

Bailey: Sixteen

Evans: Sixteen, [so, are the] results out?

Bailey: Results, yes, she got [them] yesterday, yes.

Evans: How did she get on?

Bailey: She done really, really well. The school allowed her to drop a couple of GCSEs because obviously with the amount of schooling she missed. They had a scribe for her. So she only managed to sit six exams. Lucky enough with the other seven exams, apart from one, she'd covered over 25% of the coursework. And because we'd actually managed to get an appointment with the consultant, and he could see the amount of pain [she was in], and [that] there was no way possible for her to actually sit the exams.

Gilbert: The good thing for a thirteen or fourteen or fifteen year old is, you can get back into school. And if you can get back into school that provides so much momentum, all of a sudden your day is structured, you have social contact, whether you like it or not, you're rubbing up against your peers. You've got sensible adults around you who are pushing you kindly and noting where you're at. So school is just the most tremendous asset for young people.

McCann: Taylor is exceptionally driven, [she] wants to go on and be a paediatric doctor, but Taylor has a tendency to over-push herself. She pushes and pushes and pushes with school with everything. And then she has a massive crash. And those periods where she crashes, she misses a lot of school. She's very distracted at school, she struggles to study sometimes in the evenings revising for exams, and all that kind of things as well. So, her school has been varied with regards to her time off. But obviously, the emphasis has been on Taylor to catch up. If she wants to continue on the courses that she's doing.

Evans: Your mum was saying that you're pretty driven.

Taylor: Yeah, I definitely am. I used to think it was a good thing to be so driven, but then since coming here, they've all said, 'Right, you kind of need to slow down a bit.' And it has made me realise that I keep going and going until I'm at the point where I'm like, physically sick with pain. So it's a good and a bad thing because it's gotten me to where I am today, like for a while I was in, like I used crutches for a year and a half, was in a wheelchair for going out. I had a cast on, I had a boot on, so I am a lot better than what I was like because of my drive. Then at the same time it gets you to bad places as well, where I like... end up being physically sick.

Evans: What have you learned here that might help you?

Taylor: I need to slow down and appreciate the things that I have rather than keeping on going and that sort of things.

Evans: That's booming and busting, isn't it? Yeah.

Taylor: Yeah, [I'm] quite bad for that, definitely.

Evans: Jasmin's mum Louise

Bailey: The last flare up in September caused a lot more pain. And [there were] sleepless nights. There was shouting because in the morning – I'd say, 'Come on, you've got to get out of bed.' [And she'd say,] 'I can't get out of bed. I haven't slept, I can't move my arms,' etc. So, it's the shouting and then it's the crying. So it has affected the whole family.

Evans: Does she have brothers and sisters?

Bailey: Yes, she's got a brother.

Evans: How old is he?

Bailey: He is a year older, he is seventeen.

Evans: So, they're very, very close in age.

Bailey: Yes, yes.

Evans: How has it affected him?

Bailey: Even though we don't always show it, it's a case of going to school, when he's already been listening to shouting in the morning. So, he's just finished doing his AS Levels. So sometimes saying it'll be a great start in the morning, [but] waking up to screaming and shouting.

McCann: Taylor has a ten year old sister. So, obviously it restricts what you can do as a family. It also means that sometimes Taylor is your main concern when she's been physically sick with pain. That kind of takes over from pretty much everything else that's going on at the same time, so it does definitely impact every part of family life.

Evans: Your mum was saying you've got a younger sister. How do you think your chronic pain has affected the family as a unit?

Taylor: Obviously you have bad days. It means that you can't do things that you've planned to do. So, it can affect your family life and like your family activities, going out with your family. So, then you stop socialising with them as much and it causes arguments. So, it had a detrimental effect on the family, I'd say.

Evans: How do you think it's affected your ten year old sister?

Taylor: She tries her best to understand it, but she doesn't. So, I feel like she sometimes feels a bit left out possibly because mum will be dealing with me, and she's just by herself, like if my step dad is out, so I feel like it has a big effect on her.

Evans: Have you learned anything here about how to sort of, well... live with or integrate with the family?

Taylor: On a Friday we were making weekend plans and one of the weekends, Jason and Luna came down and I planned to do family activities and I'm quite a structured person, and if I've got a plan in place I'll do it. So because of that, we went out to the beaches and we were out. So, it shows you what you're missing sort of thing. And it encourages you to spend more time with them, that you're going to be in pain anyways. So, there's no point sitting around feeling sorry for yourself, you'd be as well getting up and getting on with it as much as you can. Yeah, take breaks, that's another thing that I have learnt, is like taking breaks because before I just push myself to extremes. So, like taking breaks whilst with family, so you can do more with them. It's the boom and bust again, you don't take a break so you don't go too far.

Evans: Amyra?

Amyra: Yeah. Boom and bust. I do that a lot. It's when I push myself too much. And then I become flat out on the other days where I physically just can't get up. Because I'm just driven and just like to succeed in everything and just not take breaks because I just tend to too much on the rare good days I get and then I'm just flat out. Well, since coming here teaches you to be a bit more... not to do too much, just keep at a steady level.

Evans: That's pacing, isn't it?

Amyra: I like the satisfaction of doing something well. So pacing is very, very difficult for anybody but especially if you want satisfaction in every single thing you do,

Evans: How have they helped you here, if they have helped you?

Amyra: Mindfulness, we do a lot of checking in. And that can just help your body tell you if you just did too much or [not enough]. But also some of the exercises – the physiotherapy

side of everything does help.

Evans: You are in the middle of Bath, some of these kids might not have been outside for a long time, they get a shopping experience.

Gilbert: That is exactly a central piece of the rehab. In a way we want to make our rehab very un-hospital-like, because the rest of the world isn't like a hospital, we want kids to go into shops, go and get coffee, go and get strange like – juice mixes and things like that from the juice bar. You know, we want them to go out with each other. And you're absolutely right. These can be, for some young people, very new experiences and can be very nerve wracking. But they're absolutely a key part of the therapy. We try and use the city as a kind of rehab playground, so that young people can choose carefully graded tasks and go out and for example, be in a crowd of people, lots of young people with pain and adults with pain are very afraid of being in a crush, being in a crowd, being shoved up against other people because they're going to get jostled, bumped and looked at as well. And these are risky, difficult situations but they're things that in a sense need to be mastered. Otherwise, the young person will really never leave the house. So, we've got a chance to, you know, 'purpose design', little experiments and moments of risk taking that young people can do in Bath.

Evans: It's a very strange age, isn't it because you're a child up until the 364th day of your 17th year, the following day, you're an adult, and the whole world changes for you.

Gilbert: Even worse, the transition challenge in services is very often that paediatric services will stop seeing people when they are sixteen. And adult services will not see anybody until they are eighteen. And you could argue that those are two pretty important and sensitive years of your life. So sometimes there is actually a genuine transition gap where young people sort of dangle for lack of services. Now, people have recognised this problem for quite some time, and particularly in acute illness. So, people treating young people who have survived cancer or have chronic conditions have recognised that they can't have this disastrous gap and have made attempts to close it. But for young people with chronic pain in particular, there are very few specialist paediatric pain centres so most of them will be seen by paediatricians and paediatric rheumatologists whose remit will stop around sixteen. And then adult pain services, who to be fair, are not always best equipped to deal with nineteen year olds and their parents, because that's usually what happens. So yes, to a degree we

know about it as a service community and people are trying to do something about it. But it's still a huge risk for some young people at some parts of the country, there is this big service gap.

Evans: So as a national specialist service, people from all over the UK could come to see you.

Gilbert: That's right. They need to have been well worked up by local paediatric colleagues for it to be convincingly clear that people have done all the sensible and appropriate things that can be done locally. But after that point of view, NHS England takes the view that yes, if that's been done, then after that point any region can refer to us.

Evans: Now Amyra you're seventeen. And in terms of the health service now, you're not an adolescent, and you're not an adult. It is a two year gap between sixteen and eighteen, where you're a nothing.

Amyra: It's a very hard transition, it's very hard. They might have kept me on longer with the children side, but what happened is the doctor said, 'I can't find out what's wrong with you, bye-bye'. So, I moved on to the adults and I've still not fully transitioned, I've been with adults for a year but it's very hard because we're so young, because they say, 'Oh, the adult medicine side can open everything for you.' And it doesn't. And especially being with chronic pain, and the chronic pain service is hard when you're sat amongst eighty year olds, and you're seventeen and people don't get [to grips with the fact] that young people can have pain too. So, for me, I find it very hard, I prefer being in the children's side.

Gilbert: We've always had an eleven to eighteen adolescent programme. But then we realised that there was a group of young adults, people in their early twenties, who'd had pain since adolescence, [and were] really super struggling, [who] never really managed to get beyond their parents' house. In a sense, it's hard enough, I think in these days to get a job and be independent [and] if you've got a pain problem as well, it's double tricky. And they didn't seem to fit too well on a standard adult programme. You know, the demographics are pretty consistent, it's usually people in their forties and fifties, with back pain who've kind of had a life to a degree. And then we have these twenty-one, twenty-two year olds who just didn't seem in the same place, but weren't children anymore. So we run young adult programmes for as it were, the eighteen to thirty range as well. So we like to think we can do

the transition work all the way through.

Evans: That's Dr Jeremy Gauntlet-Gilbert, Principal Clinical Psychologist at the Bath Centre for Pain Services, and you can find more about them and the services they offer at their website which is: bathcentreforpainservices.nhs.uk, and as always, I'll remind you the small print that whilst we in Pain Concern believe information and opinions on **Airing Pain** are accurate and sound based on the best judgments 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. Don't forget that you can download all additions of **Airing Pain** from Pain Concern's website which is: painconcern.org.uk. And from the website you can tap into all the support leaflets and information on managing your chronic pain, including details of *Pain Matters Magazine*, which is now available in electronic and of course paper format. So, to end this edition of **Airing Pain** recorded on the last day of a young person's pain management programme at the Bath Centre for Pain Services. What's the verdict? Parents?

Bailey: It's made her realise [that it's] not always, 'I can't do', it has made her think, 'Well yeah, perhaps I can do this'. It has helped me realise that I need to step back, because as a parent when your child is in pain you want to basically wrap them up in cotton wool.

McCann: Taylor and I are extremely close anyway. But it's given us both ways to articulate ourselves to each other, especially [in] that role play yesterday, I think all the young people seen how they acted by somebody else acting like that, I think opened everybody's eyes, adults and young people as well.

Bailey: It's a hard course – mentally it's hard – it's draining. But what I would say is that to all children who are listening to this, stick it out, because my daughter could have quite easily have walked, you know, a few times during the course where she started talking about how she didn't like it, but she stuck it out and she's benefited from it.

Evans: So that's what the parents think of it, what about the young people? Do bear in mind Jeremy Gauntlet-Gilbert's rule of thumb from the start of this edition of **Airing Pain**.

Gilbert: They usually as you can imagine arrive fairly nervous and terrified into the group.

And one of our measures of success is the amount of noise and rowdiness we can achieve by week three.

Evans: When I came here this morning, and went into what I guess is your common room, you were on one of these big inflatable balls, I won't say you were completely out of it.

Amyra: [Laugh] how do I explain that?

Taylor: I don't know, just, we were messing about but at the same time...

Amyra: I was in my Zen, it was calming.

Taylor: Yeah.

Amyra: It was calming just sitting on the ball.

Evans: So, you were using a relaxation, you say Zen – relaxation, visualisation.

Amyra: How did we get on a ball and it turned out to be relaxing? [laughing]

Contributors:

- Dr Jeremy Gauntlet-Gilbert, Principle Clinical Psychologist at the Bath Centre for Pain Services
- Louise Bailey, parent
- Sandra McCann, parent
- Amyra, young person
- Taylor, young person.

More information:

- [Bath Centre for Pain Services](#)
- Pain Concern's leaflet: *Parenting a Child or Young Person with Chronic Pain*
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