

Airing Pain programme 99: Transition services for adolescents with chronic pain

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Going through adolescence can be a difficult process for anyone, but for young adults with chronic pain the difficulties of these formative years can become multifaceted. With 8% of young people in the 13-18 age range affected by chronic pain (15,000 living with arthritis alone), the transition to adulthood, and the medical support that accompanies it, is an important process.

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*In this edition of **Airing Pain** we explore the challenges and successes that patients, parents and healthcare professionals encounter when entering this crucial period.*

Pain management consultant Dr Mary Rose and nurse Mandy Sim of the Royal Hospital for Sick Children in Edinburgh speak to Paul Evans about the methods they use to make the transition into adulthood as supportive as possible, as well as the importance of educating patients, parents and schools on the biopsychosocial aspects of pain and its management.

Dr Alison Bliss, paediatric anaesthesia and chronic pain consultant at Leeds Children's Hospital, emphasises the importance of finding a balance between cultivating independence in young-adults with pain and helping them find the support in their transitional period.

Paul also speaks to Dr Line Caes, psychology lecturer at Stirling University, touches on the nuances in dealing with how young people see themselves in comparison to their peers and making the classroom a more accepting space.

Paul Evans: This is **Airing Pain**, a programme brought to you by *Pain Concern*, the UK charity providing information and support for those of us living with pain and for healthcare professionals. I'm Paul Evans, and this edition has been funded by a grant from the Agnes Hunter Trust.

Dr Alison Bliss: Quite a lot of paediatric services are funded and set up, up to [a child's] 16th birthday. But then a lot of adult services don't start until their 18 years. So if you're a teenager with chronic pain, [in] that sort of 16 to 18 age gap, where do you get your help from?

Evans: Chronic pain affects eight per cent of young people within the 13 to 18 age range in the UK. And to put that into perspective, 15,000 of those live with arthritis, and that's just one condition.

So in this edition of *Airing Pain* I want to focus on what happens to the care and support for those with chronic pain conditions when – according to classification – they are neither child nor adult. So when does childhood stop and adulthood start?

Dr Mary Rose is a consultant in the pain management clinic at Edinburgh's Royal Hospital for Sick Children.

Dr Mary Rose: Well there are legal definitions, in that you stop becoming a child at the age of 16, although you're able to give consent in Scotland from the age of 12 onwards. But practically when we're managing children and young people, I think we recognise that there's a distinct group, particularly the 16 to 23 or 25-year-old age group. These are what I would consider young adults rather than children, in that they have very distinct needs from children, yet there's still a lot of psychosocial development going on between the ages of 16 and 23, so that doesn't always fit very well with the model of care that we have.

Evans: Dr Mary Rose. And that model of care, to the outsider at least, seems rather baffling.

Dr Alison Bliss is a consultant in paediatric anaesthesia and chronic pain at Leeds Children's Hospital.

Bliss: When our service was originally set up we were funded for 16 years, and quite quickly we realised that actually [for] quite a lot of teenagers that's the time when they develop pain. They have nowhere to go, so we expanded our service up to 18 years. And for the vast majority of young people we hope that, while they spend their time with us, they learn the life skills and the self-efficacy that help to address their problems, so that pain doesn't go on to be a problem into their adult life. But there will be some young people for whom pain is a problem, [and] we haven't got on top of it yet; they're going to need a bit of extra help. And it's all about trying to make a joined up path, so they know where they are going to get their help from, they know where they are going to get their care from, who's going to support them as they move out of the children's services and into the adult services.

Evans: Now it's interesting you use the word children's, because the last thing a teenager would want to be called is a child. There's enough going on in a teenagers mind, from memory.

Bliss: Absolutely. It's the difference, isn't it, between the absolute horror of being sat in a waiting room full of snotty nosed children, with bits of coloured plastic sitting around

everywhere, or being sat in a waiting room full of old people looking at posters advertising walking aids and incontinence aids. You don't really fit in to either of those worlds.

But also we know that teenagers who have chronic pain, because it's coming at that crucial time when they're trying to find their sense of self, they're at a higher risk of doing risky things. Sometimes that can be from the self-harming aspect of things, if their moods are low, but also in terms of social things, for instance we know that they're at higher risk of having unprotected sex, not thinking through their decisions, trying alcohol and drugs; this is the time of life when it happens. And so we've really got to engage with the young people, and make sure that we stay engaged and that I can hand over to somebody who is also going to be engaged, because if they feel like medicine is just dropping them, then they're less likely to come to appointments, they're less likely to follow advice, they're more likely to go off and undertake these risky behaviours.

Evans: What's going on that makes them do these risky things?

Bliss: I don't think anybody knows exactly what's driving that, but there are some themes that we think are becoming really apparent. So we know that if you're in pain every day and there's nothing to see for it, there's that sense that you're not being believed and that makes you feel very isolated and alone. And if you have a condition that means you can't keep up with your friends, you can't walk round town all day, you can't get out and do these activities, then, again, it's that sense of isolation. And sometimes it's desperation: people don't believe me, they don't know what I'm going through, I've got no other way of letting out these emotions.

And so when I see young people in my clinic the first time I meet them, I meet them alongside my clinical psychologist, and a part of that consultation is about thinking about the impact of pain on mood, and how low that mood gets. And how they're coping with that, and where they're accessing any help and trying to pick out right from the start anyone who is at risk from those self-harm ideas and thoughts, and whether there's anyone there to help support them through that.

Evans: One of the things about being a teenager is actually, you don't want Mum sitting next to you when personal things are happening in your life, but you do need that support, but you'd like it to be invisible.

Bliss: Yes, one of the big things about being a teenager is [that] it's that one time in your life when you're struggling to find your own sense of self, and you desperately, desperately don't want to stand out from anybody else. And for teenagers with chronic pain that's really hard because you have something that makes you disengage to a certain extent, you can't do the

things that your friends do, but they can't see a reason why. And then it's hard to talk about it to your friends, hard to talk about it at school or college. And so quite a lot of our young people go through a lot of unnecessary suffering because they don't know how to share that information with the people around them, to find the support they need, and the independence they need at the same time. It's a mix of both things.

Evans: It's hard for parents as well.

Bliss: It's very hard for parents, particularly for parents who've now got teenagers that started out as a young child with a chronic condition, where for a long time they'll have been working super hard being the advocate for their child, making sure their child gets all the help they need. And sometimes accessing chronic pain services for children is quite tricky because there aren't so many of us around, so they may have had to battle for a long time. And for us to turn around and say, 'and now it's OK to let go' – that's a hard process, and it's about making sure that if we start that from the paediatric side of things, we've got a counterpart waiting to pick up and carry on that process on the other side. So we're becoming increasingly aware of it, but up until the last couple of years it's really been patchy about what happens for these new adults.

Evans: But is it as simple as that then, you've finished one service, you're 17 on the Monday, you just turn up and say where do we pick up from here?

Bliss: It's very difficult. We recognise that actually for a lot of our young people it's not based on chronological age. We see some 18-year-olds who are about to possibly go to university, but have been very much still in that shared responsibility of the family – they're not used to making decisions by themselves, they've been in full time education, they've been experiencing life as an older child. And for them really to say, that's it off you go into adult land, that's quite hard. Whereas actually we've got some 16-year-olds that are already seeking independence, they've decided they're moving out from school, they're going to college, some of them are making plans to live independently. Which they're allowed to do, that's fine, and for them actually they are ready for adult services possibly that little bit earlier. It's trying to find the right balance, and ultimately what you can access in your area to a certain extent depends on what you're funded for, and that's where we have problems.

Evans: That's Dr Alison Bliss, consultant in paediatric anaesthesia and chronic pain at Leeds Children's Hospital.

Dr Mary Rose again.

Rose: As well as having to deal with all the changes that everybody going through adolescence deals with, these young people are having to deal with the fact that they have a

chronic disease that impacts on their ability to go to school and their ability to socialise with their peer group. Any young person, as they become an adolescent, they have an awful lot going on. All the changes with puberty, and the pushing the boundaries and risk taking – although I think there's a tendency for patients who have a chronic condition, [who] sometimes may have been a bit held back, then they'll be less independent, less likely to be showing some of the age appropriate behaviours. So there's a degree of wanting to normalise that with patients that we see.

We do provide quite an ongoing service to them – they're able to contact the pain management nurses, they can phone up when they need to – and I think just by the nature of the pressure on adult services, that kind of ongoing availability of support isn't there. I think [with] the adult services, a patient will be seen in adult services and then generally advice [will be] given to their GP as to how they should be managed. So we're very aware of that when we are seeing young people, and aware that they may transition on to adult services, [we're] making them aware that the services will be different.

Evans: Adults faced with pain management issues, self-management issues, would think about things from an adult point of view – well, hopefully – a much more mature point of view. Getting over self-management messages [to young adults], pacing and things like that, it's a bit more complex isn't it?

Rose: It is, and I think it's key to what we do in the clinic. I think one of the most important things that I do, rather than prescribing medicines, or referring to physiotherapists, is giving the formulation, and explaining the biosocial model for pain. And that's how I draw in why self-management techniques work, I give quite detailed explanations about pain transmission and why techniques such as relaxation and distraction and psychological therapies do have a role.

Evans: Doctor Mary Rose.

Mandy Sim is a pain nurse specialist at Edinburgh's Royal Hospital for Sick Children. So what are those self-management techniques and messages she reinforces to patients and parents?

Mandy Sim: Medication is not a long term answer. The use of relaxation techniques have to be practiced, it's not something you become good at straight away. So I would always encourage them to maybe build it into their night time routine, so you're practicing it, which might also have an impact on your sleep. But it also means that by practicing these techniques, when you're having a bad day, you automatically go straight into these techniques and you're not having to overthink about how to do [these techniques], because

you're obviously thinking about that, but your mind's busy because you're sore, so it becomes second nature to them. So these techniques have to be practiced, I think that's the big message.

And this is not something that you're going to get through to these young people on your very first appointment with them. But we know these children sometimes for a number of years. So you build up a relationship, you build up a rapport with them, and at that stage they're more likely to listen.

Evans: So you're growing the relationship with them – when they go to the secondary school, when they cease to become children and become young adults, you're actually growing with them.

Sim: Yeah, absolutely. And it's not [that they] come to clinic and then we don't have any contact with them again till the next clinic. We pick up the phone, [and say] 'we saw you six weeks ago at [the] clinic, how's the treatment that we introduced that time?' There is a rapport building up, the families feel that you're interested in them because you're picking up the phone to find out how you're getting on. With the young people, ideally I try to speak to them directly, rather than just going through the parents, so again you've got that rapport, and that relationship building with them.

Rose: I suppose the other key important message is that you use self-management strategies and exercise, regardless of whether the pain is there or not; you don't wait for the pain to go away and then start doing this.

Sim: These strategies also, they're lifelong and they support the young person, not just with their pain, but any stressful experiences in their lives, so sitting exams, sitting their driving test, moving away from home. So these strategies they're learning, they're not just relevant for pain, they're relevant for so many things in their life.

Evans: That was Mandy Sim.

Now with the biosocial model for chronic pain, the two social environments a child spends most time in are home and school. Doctor Line Caes is a psychology lecturer at the University of Stirling's school of natural science. Her research interests are in the psychosocial aspects of children's pain.

Dr Line Caes: Children don't live with their pain on their own, they share it with their parents, [and] parents respond to their child's pain. But also children actually spend quite a lot of time in school, even when they're in pain, so we're looking at how teachers are dealing with that, and how teachers can be supportive of a child who has chronic pain.

Evans: So that's very interesting, because most chronic pain conditions are invisible.

Caes: And for these kids that is a bit of a mixed bag, because they do want to be like every other child, they don't want to be treated special. So the fact that pain is invisible is important in that sense; but on the other hand, because it is invisible, when they really need help it's also difficult sometimes to get help, and to get heard because somebody is saying, 'but you were dancing yesterday, and this morning you can't be in school and write your essay, so what's going on there?' So because it's invisible it's difficult to get heard and to get help when they need help.

Children can live as normal a life as possible even if they have chronic pain, and it's actually important that they learn to be normal children, and we call it learning to be resilient. And you can laugh if you have chronic pain, you can have joy, you can have pleasure, you can go out with your friends. I think the most important thing for these kids with chronic pain, is that we realise that they have to pace themselves more. So yes they can go out at night, they can play with their friends, but probably the next day they'll have to rest and do more relaxing. And that's what we call pacing: they can't [exert themselves] every single day, they're not having an extended amount of energy, they need to rest and compensate for [it] if they went out with friends, for example.

Evans: That's good advice I'm sure for the person with pain, for the child or adolescent with pain. But of course it's two way travel: the teacher, what should they know?

Caes: We interviewed eight teachers, across seven different schools, to see what they want to know. They had experience of having a child in their classroom with chronic pain for at least one year, and we asked them, 'what would you want to know, what were you missing, to help that child in an effective way?' And they do say training – 'we need to know practical tips on how to handle the chronic pain in the classroom' – because the main thing that teachers now do is they pick up the phone and they call the parent and say, 'your child is really not feeling well and you need to come and pick her up and take her home.' But they realise that that's actually detrimental, that's negatively affecting their academic performance, their ability to engage with their peers and have social interactions, and learn from those social interactions.

So they really want to be trained on helping those children with chronic pain. And I think one thing is to learn that it's invisible and you can't always immediately see what's going on, so you really need to check in with the child every now and then, [ask them] 'how are you doing?' And that pacing, it isn't because yesterday that child was looking well and was taking part in the class, that [therefore] the next day it will be the same; [the] next day can be

entirely the opposite. So I think learning that it can switch in a second, and switch quite quickly for a child with chronic pain, is one of the important things to learn.

Evans: As you said, a child, or a teenager, an adolescent wants to appear normal, but there's always the danger that having coached the teacher, if you like, how to deal with this, he or she is pulling that child out of the normal group and setting them elsewhere.

Caes: That is a tricky balance to find. One example was, for instance, a child that we spoke to who had juvenile idiopathic arthritis, and have difficulties walking up the stairs, so the school allowed her to use the elevator – but she'd rather crawl up the stairs that use the elevator, because she was the only child in her class allowed to use the elevator and she didn't want to stand out.

So it's finding that tricky balance, and I think from the interviews we did with the teachers, they had actually quite nice suggestions I hadn't thought of. The teachers have a curriculum they have to teach, they have a whole lot of biology they have to address, [of] geography [and] history, and they were like, 'why don't we have a curriculum about pain, a whole set of materials that we can put in the curriculum and teach the whole class about pain, and about what chronic pain is, that children can also get chronic pain, and children can also get juvenile idiopathic arthritis and it's not just a disease for old people.' Then they were like, 'you can pay attention to the child, you don't have to point the child out, but you [can] address chronic pain with the entire class as part of the curriculum, and everybody is learning about chronic pain and how to deal with chronic pain.' And I think all children can benefit from it. And so you're addressing the needs of the child with chronic pain without pointing the child out and having it stand out in the class. And when we were talking with the teachers [I thought] that's brilliant, I hadn't thought of that?

Evans: Well it is a fantastic idea, but I think many teachers would say yes it's a fantastic idea, but this is just another burden on the overcrowded curriculum?

Caes: But in the one sense it's already a very busy curriculum, but now they have to address a child with chronic pain, they have to address the needs of the child with chronic pain, in addition to that overcrowded curriculum. So they were saying probably something has to make space for adding that to the curriculum – fair enough, everything is important. So there is always making that balance, but now it's coming into addition there anyway, and the teachers realise that there's more and more kids with pain, or with disabilities in the classroom, and there's more and more prevalence and it will become probably more and more prevalent in the future. So that is one thing that they feel is possible to address, becomes now it comes in addition to that busy curriculum.

Evans: Doctor Line Caes of Stirling University in Scotland. That particular study of hers was done with primary school teachers, but the results do concur with other studies involving secondary schools.

Now, pain education in schools is not as fanciful as you might think. Mandy Sim, a pain nurse specialist at Edinburgh's Royal Hospital for Sick Children, is at the front line – or the coal face if you like – of support for the Pain Management Clinic. And the front line does indeed reach into her patient's classrooms.

Sim: It is giving them support to cope with changes that they're going through. Supporting them with being able to engage with their peer group, with education; supporting the schools to understand what the physical condition is, what the needs of the young person are, and being able to put things into place to support that child to get into school, to get their education, to get their peer group, and get them socialised so they can become the young adult that they're going to become.

Evans: So you're talking to the world around the young adult?

Sim: Yeah, absolutely – so involving parents, involving the school, are there are community services available. And sometimes even the peer group. So I have been known to go into the class and speak to the class about chronic pain, how it affects young people, how they behave when they've got pain and some of the treatments that we use to help them manage their chronic pain.

Evans: So what would you tell them?

Sim: I speak to the young person who is concerned, and say, 'do you want your peer group to know that I know you, or am I just coming out as this is my role?' So I will explain what my role is, talk about chronic pain, try to engage the class to get them to say what sort of things might cause pain, how might I know has somebody got pain. It's a very two-way session that I do. And then [we] look at things that we would do to provide some pain relief for the young person, to get them into school, and hopefully to get their peer group to understand that you don't have to have a plaster on your arm, you don't have to have a scar, to have pain. It might be something that's actually quite invisible, but actually you could have pain that's there every single day.

Evans: I remember talking to a friend who was a wheelchair user and her showing me round her old school. Things that I thought were absolutely fine, simple things like timetabling, you can be [in] room one for something, then your next lesson [is] in room ten. And nobody's taken into account the one stair that you have to get through. So the whole aspect of dealing with people with physical disabilities has to be rethought.

Sim: Well we look at things like getting out of class early, so they're missing the hustle and bustle of the corridor, potentially having a buddy that can support them through the corridors, maybe having two sets of books, so they've got a set of books that's at home and a set of books that's in class so they're not having to carry books back and forth. So there can be lots of what we'd perceive as quite simple fixes, but it makes a huge difference to the young person.

Evans: It's a lot of thought isn't it, and yet again, not a lot of thought, to sort these things out.

Sim: And it's that face-to-face, or that telephone communication with the teacher, and that [communication] – [whether] I'm phoning from the pain clinic, I'm phoning from the hospital – that opening line of the communication makes such a difference to the young person, [knowing] that they've got that level of support.

Rose: I think a really important message that you get across is that these young people are going to have good days and bad days as well, which we sometimes find the schools struggle to understand: why a young person one day can do lots of things, but then for the next few days they can't.

Evans: It seems to me that young people might get better treatment in that respect, from the biopsychosocial [aspect], from the social aspect; young people may get better treatment than adults.

Sim: Yeah, I think from the social, and the engaging with the peer group and education. I don't know what goes on in adult services, but I would possibly agree.

Evans: Well for somebody with chronic pain – I have chronic pain – the thought of somebody coming in and explaining to my friends and colleagues, and my bosses what is going on, would have been very helpful.

Sim: And the feedback that we get from both schools, from the young person concerned and from the parents, [shows] they very much appreciate that on the coal face front, coming out and speaking to people and being visible, they find that very helpful.

Evans: That was Mandy Sim.

Here's Doctor Alison Bliss, consultant in paediatric anaesthesia and chronic pain at Leeds Children's Hospital again.

Bliss: Adolescents, they're a group in their own right, and we need to up our game really.

Evans: How do you do that?

Bliss: It's about trying to make it a process, so we're now starting to change the environment that we see these young people in: giving them information right from the start, to say, 'it's OK if you spend a bit of time with us, without mum and dad there – we can split our consultation so that you can come and talk to me by yourself, or talk to our nurse by yourself, and then we'll join mum and dad in and help manage things on.' Because when you go out into adult land, you'll be asked to go in by yourself, and the amount of support you get from your parents is going to lessen.

Evans: That's Doctor Alison Bliss in Leeds Children's Hospital.

What about Edinburgh? Doctor Mary Rose.

Rose: We would definitely continue to see them once they remain in full time school education, so we're happy to see them up to 18. If we get a new referral for a patient aged 17 or so, we say, 'if we see them they're not going to stay in our service very long.' So we may prefer them to start their journey in adult services, which I realise is quite tough for these young people. So when we do transition we always make contact with the adult chronic pain services first of all. And they are – certainly within Edinburgh – there's one of the consultants [who] has an interest in young people in this age group, and also one of the psychologists does as well, so we'll be in touch with them before, and we'll do a joint appointment as the first appointment as well. So that we can be clear about the purposes of the transition, what we're expecting from transition, so that the young person and their family feels supported when they do start attending adult services.

Evans: Having, as you've said, grown with these young adults from possibly a very early age, they might feel cocooned and loved, and [then] that carpet is taken away from them, that loving feeling.

Sim: Yeah, and it's something that we've been very aware of. We've kind of grown with them over the years, and as we're getting closer to that transition, there are maybe slightly fewer phone calls; we're just trying to promote a bit more self-management so they're not going from phone calls from the pain team every six weeks to 'off you go into adult services.' So it's like letting your child go: you're just giving them a little bit more independence, yeah, managing their own symptoms a little bit more. We're there in the background, you can contact us if there's any problems, but [still] just giving [them] that bit more independence as we're coming up to transition.

Evans: That's Mandy Sim, pain nurse specialist at the Royal Hospital for Sick Children in Edinburgh.

Now as always I have to read you the small print, that whilst we in *Pain Concern* 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.

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Now, I just want to end this edition of ***Airing Pain*** with advice for parents whose children – or are they adults? – anyway, young adults, as they leave paediatric services. Doctors Alison Bliss and Mary Rose.

Bliss: There are some things that you need to support them and let them do these things for themselves, and give them that little bit of independence as they're going along, and that's hard. It's hard when you've had a child with a chronic condition, a teenager with chronic pain, [who] are often a lot more dependent on their parents than the typical teenager. And it's being able to find that right balance to support the young person as they gain increasing independence and to support the parents, to say at times it's OK to let go.

Rose: It's hard being a parent anyway, [even] if your child doesn't have a chronic condition, so I recognise it must be even harder for parents of children and young people with chronic conditions to let them go and to encourage them to become more independent, but it's the right thing for them to achieve their full potential.

Contributors:

- Dr Mary Rose, consultant at the pain management clinic at Edinburgh's Sick Children's Hospital
- Mandy Sim, pain nurse specialist at Edinburgh's Sick Children's Hospital pain management clinic
- Dr Alison Bliss, consultant in paediatric anaesthesia and chronic pain at Leeds Children's Hospital
- Dr Line Caes, psychology lecturer at University of Stirling's School of Natural Science, researcher in paediatric psychology and psychological aspects of children's pain

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