

Programme 106: Pain Education for Doctors, Patients and Parents

What can be done to implement better pain education for doctors, patients and parents, and trusting your pharmacist when in doubt

This edition has been funded by Pain Concern supporter and cyclist Ade and The Sackler Trust.

*According to the British Pain Society, doctors and other healthcare professionals (HCPs) receive less training in pain management than veterinarians. With pain being one of the major presenting factors for a large number of medical problems, this edition of **Airing Pain** looks into what programmes are being implemented to alleviate this knowledge gap.*

Dr Helen Lakins, deputy lead for the UK Essential Pain Management Course, describes how the course developed from being taught to HCPs in developing countries to being used in Australia and the UK. The predominant aim of the course is in response to the majority of medical undergraduates believing they are not receiving adequate pain training.

Swansea University is currently undertaking a research study into patients' beliefs and expectations of pain medications. Paul speaks to Dr Sherrill Snelgrove and Sarah Long about how the study has found evidence that people's beliefs about their medication and illness can feed into how they manage their pain.

Finally, Paul speaks to psychologist Dr Jo McParland of Glasgow Caledonian University about her involvement in a study focusing on parent appraisals of injustice when their child has chronic pain. Dr McParland emphasises the importance of highlighting the child's experience, as well as validation from both HCPs and parents themselves.

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 the Sackler Trust, and cast your mind back to edition 102 of **Airing Pain** when I spoke to cyclist Ade about how long distance cycling offers him considerable relief from the grind of his daily constant pain. He was about to embark on his 21 Days of Pain challenge, with a target of cycling 60 miles each day for 21 consecutive days. And that's a mind blowing 1,260 miles.

Ade: It's not just a fundraising thing, this is a way of showing people that by doing something physical you can manage your own pain.

Evans: Well Ade's 60 miles a day was a rather conservative target, check out his ride reports on 21daysofpain.org.uk. They're a really good read, a really informative read on how self-management of your chronic pain really can work.

Ade: Once you find something that helps you ease the pain, you kind of latch on to it. It was doing more than the pain medication.

Evans: And you'll notice that he exceeded his target by 550 miles, a staggering 1,810 miles in total. We can only thank him for donating the money he raised to help support this edition of *Airing Pain*, in which I'm going to look at three areas of knowledge building, affecting the young:

Joanna McParland: Within a school context, a child was reported to be having pain and saying they couldn't participate in activities because they had pain at a particular time, but they were informed by the teacher, according to the parent, to get on with it, suck it up and just get on with it.

Evans: The old:

Sherrill Snelgrove: Sometimes people of a certain generation are reluctant to question the medical regime that they're on. We're interested in how we can help people to question or think about the medications they are on themselves and the side effects.

Evans: But we're going to start with the health professionals who treat us. Helen Makins is a pain consultant in Gloucestershire Hospitals NHS Trust. She also has a role in The Royal College of Anaesthetists' Faculty of Pain Medicine as deputy lead for the essential pain management course in the UK.

So what is that?

Helen Makins: It's a course to teach healthcare professionals about the basis of pain. So it follows an algorithmic approach, a bit like when we do resuscitation, we follow an ABC approach, with this we follow something called RAT, which stands for recognise, assess and treat. And through those three parts of the teaching we investigate all the different options available for recognising, assessing and treatment of pain.

Evans: ABC I know from my first aid course is airways, breathing, circulation. And what's the one you were saying?

Makins: RAT, so it spells rat. And we like to say that pain is a bit like a rat, in other words most people don't like pain, it's a really unpleasant thing, but often you can't see it, so it's relevant in that respect as well. And it happens to stand for recognise, assess and treat.

So originally the course was developed in Australia and at that time it was devised as a course to teach healthcare professionals in developing countries how to manage pain. And then the team who had started teaching it abroad realised that actually their own local medical students didn't have such effective teaching. And so they started using it in medical schools in Australia initially, and then the Faculty of Pain Medicine worked collaboratively with them and brought it over to the UK. And since 2014, when we did our pilot at Bristol

Medical School, we've been rolling it out across medical schools in the UK. And the next phase, which we're just embarking on at the moment, is to take it to other healthcare professionals, non-doctors.

Evans: I mean the British Pain Society often quote this, this business, that doctors in the UK get less training in pain management than a vet. So this is something to address that shortfall?

Makins: Absolutely, and that's not just the case for doctors in the UK, there was work done a few years ago by Emma Briggs and her colleagues which showed that all undergraduates in healthcare in the UK had a really severe lack of pain training, and that, yes, this is certainly trying to address that.

Evans: OK, recognise, what does that mean? I think I know what it means, but what do you tell the doctors, or the undergraduates about recognition?

Makins: So it's about the healthcare professionals recognising the patient has pain, but also making sure their family and their friends and their colleagues and the rest of society recognise that they have pain. And also recognising the impact of that on society as well as on the individual.

Evans: Surely, they don't have to recognise pain because a person would go to a health professional because he has pain. So I don't understand that you have to train somebody to recognise it.

Makins: There are a variety of different presentations for pain, sometimes people don't necessarily say that they have pain, particularly cultural influences can affect that, especially when we're teaching this abroad or indeed to patients who are not necessarily British, but they may be living in Britain, they may be very reluctant to talk about pain, because they perceive it as a sign of weakness, or perhaps because they think nobody can do anything about it.

Evans: Okay, so we've recognised it. Assessment.

Makins: So we look at pain in quite a simplistic way in terms of assessing, so we ask the healthcare professional to ask questions of the patient, and we will be looking for the type of pain in the first instance. So we break it down into either nociceptive or neuropathic pain, so that pain that's either coming from damage to tissues directly or from the nerves. Then we look at whether it's chronic or acute pain, acute pain being pain that's short-lived, and recent onset chronic pain being pain that's been there for more than three months. And then we look at whether it's cancer or non-cancer pain. So we try to categorise the pain as the first thing.

Evans: I'm intrigued to know what the students think about pain before being introduced to pain.

Makins: So one of the things that we've brought in recently is an evaluation spreadsheet, or form, for seeing how effective this pain training is. And we were looking at what things we wanted to assess when we devised that, and one of the things we wanted to know was how much people felt that there was a need for this training at the beginning of the course. Partly as a way of sort of showing them why we're doing it. And that has always revealed when we've asked the questions, have you had adequate pain training in the past? The answer is pretty much always no. Would you like more pain training? The answer is pretty much always yes. And do you feel that all undergraduates have adequate pain training? The answer is pretty much always no.

Evans: I guess that's part of the pain problem, if you like, that it's not considered a condition in its own right. Does that affect the way the young doctors, the undergraduates, feel about it?

Makins: I think that's the way they've often thought of it prior to doing this course. Because pain training up until that point is very fragmented. They tend to get a bit of the physiology and the physiology lectures at medical school and then a bit of the pharmacology in that section of medical school. And it's never brought together. So it's sort of seen as part of many things rather than, as you say, its own entity. And this is very much bringing everything together. So all the theoretical knowledge that they already have, putting it together to translate that into how you would manage a patient.

Evans: Okay, we've recognised, we've assessed, and now we want to treat. What do you tell them about that?

Makins: We always talk about medicine options and non-medicine options. So we try and take a holistic approach to the patient. So we talk a lot about alternative therapies which may be available depending on the climate or where the patient is living. We also talk a lot about pain self-management, which is one of the key things that I think we do in the UK for management of patient particularly with chronic pain. And we explain how that helps and what that involves, because a lot of professionals haven't ever come across that before in their working lives. And then obviously we cover the pharmacological aspects and the treatments with medications.

Evans: Are you surprised that a lot of health professionals haven't come across self-management techniques?

Makins: I suppose I'm not surprised, because before I'd done pain, myself, I haven't come across it. So it's not surprising in that respect. But I do think it's quite shocking that when you

consider that pain is one of the major presenting factors for such a large number of problems in medicine, that it doesn't have a larger component in the undergraduate curriculum.

Evans: And that may come from the fact that the treatments you have to treat pain, that maybe the undergraduates, the people go into the profession thinking they're going to treat pain, with drugs, pain is something that we can cure.

Makins: And I think that is the case, people think about the pharmacology and which medication they can give, whether they're not aware, or they just don't think of all the other simple things that we can do like elevating a swollen leg, for example, or putting an ice pack on it. These things frequently get forgotten.

Makins: That's Dr Helen Makins. Well that pharmacology or pain medication is the subject of a research study being carried out at Swansea University at the moment. Dr Sherrill Snelgrove is Associate Professor at the University's Department of Public Health Policy and Social Studies. The study, which is funded by the Welsh Pain Society is confined to people living within the Abertawe Bro Morgannwg University Health Board, that's in South Wales, but the findings could have universal significance.

Snelgrove: The research study is about exploring people's expectations and beliefs about the medications. People who are receiving multiple medications may have side effects and we're interested in their understanding of the medications and the side effects. And whether perhaps some people will accept the side effects as the norm if you like and not question them, or believe that there's no opportunity for change, and become a little bit unquestioning about the medications.

There's a lot of evidence to suggest that people's beliefs, their health beliefs, their beliefs about their medications, their beliefs about their illnesses, feed into the way people manage their own condition. We're trying to engage with people who perhaps aren't being engaged with, in terms of the literature, the academic literature, and in terms of knowledge as much as previously.

So what we decided to do was to ask people who are having medication reviews, about their medications and their experiences of chronic pain. And we've been trying to do this through inviting them to an interview, a face-to-face interview where they can talk quite freely and confidentially about their experiences. And we've also given them a short questionnaire. So we have been in care homes, residential nursing homes, to interview people, and we're also interested in people who live in their own homes or visit the GP.

Evans: Talking about beliefs, I would think that many people of a certain generation would think that if doctor prescribes a medicine, it's going to work. And that's it, full stop.

Snelgrove: And that's what we're really interested in is the degree of compliance of people, of individuals. People might think that because that medication was prescribed, that it can't

be changed, and that they have to accept it for a number of years. But, sometimes, people of a certain generation are reluctant to question the medical regime that they're on. And so we're interested in how we can help people to question or think about the medications they are on themselves and the side effects.

Evans: Collaborating with Sherrill Snelgrove in this study, at the coalface, if you like, is Sarah Long. She's a primary care pharmacist working for the Abertawe Bro Morgannwg University Health Board in South Wales, and she works across three GP practices in the region.

Sarah Long: We work within the GP practice, so we can access patients' notes, and discuss with the doctors any particular issues. We also make sure that people are having the right blood tests if they're on particularly toxic medications, to make sure there's a cycle of blood tests going on.

Evans: But what can you as a pharmacist tell a patient the doctor couldn't?

Long: Well, generally we have more time. Generally, when the doctor is called, they're dealing with one particular single issue. Whereas we look at the whole of the medication list and the whole of the different chronic diseases that a patient may have, of which pain maybe one. So we look at the combinations of the drugs, make sure that they're in context with how the patient's feeling at that particular time. So I'd say the main benefit is that we can spend a bit more time; also it's bit like being a detective, you can look into the past notes and records and work out whether something that the patient is now taking is really advisable. Because the evidence base may have changed and when they were started, perhaps 20 years ago, that might have been the best drug, but science may have moved on. They may be alternatives, perhaps fewer side effects that they can be usefully switched to.

Evans: Because many people, especially with chronic pain, and maybe the elderly take cocktails of drugs, don't they? Each one may be perfectly good for what it was intended for but may react differently with another drug that they're taking.

Long: Yeah, we call that polypharmacy. And polypharmacy isn't necessarily a bad thing, because if you've got lots of conditions and symptoms and disease, you will need a lot of drugs. But sometimes other drugs started to combat the effects of the main drugs, and it all, in sort of the mists of time, becomes a bit confusing. And obviously people's bodies change over time. And during even a year, people may experience less or more of a particular side effects so their medication will need to be tweaked. So I would say we're looking after this a bit like an MOT, in that we're looking at not just the evidence base for the drugs and the patient notes, but we're also finding out what the patients themselves are currently experiencing and making modifications with that in mind.

Evans: You deal a lot, you were saying, with more elderly people. What, without pre-empting the study, what do you think the general beliefs are about medicines?

Long: Some people come at it from different angles in that I come across elderly people who take the prescriptions religiously, as per the directions on the boxes. And there are other people who pick and mix a bit depending on how they are on different days. Sometimes people I've come across are not keen to divulge to their GP that they've decided not to take something because perhaps they're having a side effect. Sometimes people also buy things over the counter or online and don't think to mention it, which sometimes can interact with the prescription medication.

And the other element is that some of the patients are being seen by multiple professionals with different specialties. So sometimes they get into a bit of a muddle and some people will then at that point use a medication review as a good time to question whether all these things go together and whether any symptoms that they're experiencing are due to the medication clashes, whereas other people might not use the opportunity. So it's about questioning them, how have they been since perhaps they started a new medication and dropped another one off.

Evans: If I, or somebody else did want to drop my medication, or just to see what life is like without it, who's the best person to talk to?

Long: Well, as a pharmacist, I would say speak to your pharmacist. Of course, if the GP is present with you at the time, talk to the GP, or the nurse, but if you've suddenly woken up thinking, this is what I want to do, then your community pharmacist that supplies your medication if you're living at home, would be ideal. Or if you're going to have a medication review, or perhaps you might want to request a medication review of any pharmacist in order to discuss the best way to stop some of the medication.

Evans: Sherrill, your research project that you're both involved with, is confined to this part of South Wales but the results will be universally important. It affects everybody, doesn't it?

Snelgrove: Well, it does affect everybody. And because it's in one particular area, it probably would be difficult to generalise but if we get enough results, it would give us a good indication of trends, patterns, people's opinions, and will be a start to doing a much larger study.

Evans: The questionnaire is very easy, although you have to think before you answer. When I did it, it made me think much more about what's going on. Just simple beliefs. Questions like: my health at present depends on my medication, having to take medications worries me, my life would be impossible without my medication. And this is pick one of these. But actually, you have to think quite carefully about it. I mean, does my health really depend on

medication? Could I be without it? How have I ever tried being without it? What should I do if I wanted to try and live without it? You know, it's a good thought-provoking questionnaire.

Snelgrove: Well, maybe, yeah, maybe completing the questionnaire has a side effect in itself of enabling you to think a little bit more about your medications. My health at present depends on my medication, having to take medications worries me. These are all questions which have been validated in other studies. But we can find out more about those answers through an interview. And when I say interview, it's not a formal interview, it's like a discussion, it's a chat. I'm very happy for the person to tell me about their experiences, their worries, their concerns. And as I said before, it's confidential, it's anonymous.

Evans: That's Sherrill Snelgrove of Swansea University. Now if you do live within the area covered by the Abertawe Bro Morgannwg University Health Board, that's roughly from Bridgend to Swansea and all points in between in South Wales. If you've been taking medications for at least three months and you've discussed your medications with a GP or pharmacist within the last 12 months, then do get in touch with Sherrill. Just put her name Sherrill Snelgrove, followed by Swansea University into a search engine, and all her contact details should come up. And if all that fails, just get in touch with us at Pain Concern, and we'll pass on your details.

Now if, as seems apparent, the participants in that study will be predominantly in the older age group, Dr Jo McParland, who's a senior lecturer in psychology at Glasgow Caledonian University is involved in the study at the other end of the age spectrum. The study she's involved with is looking at parental appraisals of injustice when their child has a chronic pain condition.

McParland: We were interested to find out about what it was that really mothers thought was unfair in the context of having a child with pain, both from their own perspective, and from their view of their child's experience of their pain condition and the impact that it has on their child. What we found was that the mothers tended to focus on their child's experience, not their own experience, and the interactions that they had with various people to try and support their child.

The key themes that I'm kind of finding is that there's an element of taking perspective, they acknowledged that their child's situation, their child's condition, was unfair, but they tended to think that's not useful to think in that way. That's not helpful to helping me to support my child. And so instead, what they did was they took perspective, by saying things like, it could be worse, there are a lot of families who have circumstances worse than ours, so we'll get through whatever it is that we're experiencing. And attached to that, related to that, is a sense of just deal with it. There's a fatalistic perspective that everybody just has to deal with the cards life hands to you. So they kind of thought, well, it's not great, but we have our struggles at times but, you just get on with it. That was very much a kind of key theme. This

whole taking perspective, imagining things could be worse, just deal with what life hands to you. And this was at times used to reject the idea that the experience their child's pain is unfair. So that was one of the themes that kind of emerged across the groups.

The second key theme that emerged was a lack of validation. Now, this is quite a big theme across the groups. And I kind of define this in relation to the fact that the parents talked about how other people, such as family, friends and healthcare professionals, kind of almost didn't believe necessarily that the child had as much pain as they were reporting that they had. Because it was difficult to understand. To kind of illustrate that, one of the sub-themes within this lack of validation superordinate theme was, he looks like a big strong boy. This is a statement that comes from one of the mothers in one of the groups and this mother reported that people just look at her child and found it difficult that her child found it tough going to school, and being able to participate in activities, because he had this pain condition, but he looked so well. So there was a difficulty from other people in trying to understand the child's condition.

There was also the parent reporting that they felt as if they were classed being an overanxious parent, because they kept taking their child to healthcare professionals for treatment. But the healthcare professional might say: 'Well you know it can't be as bad as all that, they can't be in as much pain surely as they're reporting.' The parent then felt like they were being questioned in terms of, they were maybe being overanxious in taking their child for care, when the child didn't actually need to be there. And they were starting to wonder, is it me, is it me being overanxious? Am I making my child's pain out to be worse than it is? Am I overreacting by taking my child for treatment? So this was all kind of part of this, again, lack of validation theme.

And one of the other themes that I took, well sub-themes within the lack of validation theme that I took, was from one of the groups and I titled it '*Suck it up, buttercup*'. And this was from within a school context, their child was reported to having pain and saying that they couldn't participate in activity because they had pain at a particular time. But they were informed by the teacher, according to the parent, to get on with it, suck it up and just get on with it. And within this sub-theme, parents are reporting that their child's pain is not well recognised and understood as other conditions. And they wouldn't wish another condition on the child, but they just felt like their child's pain was not supported or validated as well as other conditions. Related to that, they also reported that their child's situation wasn't treated the same as other people, who may have had injury. They were recognised as having harmed themselves and were given appropriate support, whereas their child is told to get on with it, when they have this long-term pain condition.

Evans: It's really interesting because lots of the things you say now relate to anybody with chronic pain, you can't see pain, you don't know how other people are viewing you. But for

the healthcare professional, and the child actually, taking the parent, well the mother in your case, taking that out of things, how does a health care professional work out the extent of a child's pain, but leaving the mother out of it, the mother has to be there.

McParland: It's interesting what you're saying there because, not reported here, but one of the things that did appear in the transcripts was, I think at least one or two mothers would say their child would present to the healthcare professional and would look to the mother, for the mother to tell the healthcare professional about their condition. Because it was almost a sense of, I don't know whether it was the child was unable to articulate for themselves what their position was, how they felt about the situation, what the reality of their situation was.

And there were also mothers who reported that their child would be so ill and having terrible troubles at home and the child would be in pain at home. She kind of saw the real child at home, the real state of their condition at home. But then when they would sit in front of the healthcare professional, their child would tell the professional that that they were ok and have a big smiley face. And the mother would then naturally be frustrated that the child didn't actually tell the healthcare professional the reality of how they've been suffering and been unable to participate in activities etc.

Mothers equally also say that there were days when, because pain is so variable, sometimes their child could go and climb trees or a go outside and participate in activities. Then a little while later come in and say they can't do their homework because they're in too much pain. And it's like, how can this be possible, you were able to participate in activity and now you can't. So there was almost some small element of struggle amongst the mothers to try and gauge the reality of their child's pain, and one or two of the mothers did actually say they do kind of understand that it can be difficult for other people to understand the reality of the child's condition, because they too sometimes wonder whether or not the child's actually in pain, or how much pain, whether they're in so much pain that they can't undertake activity like go to school or something like that.

We had one third theme that kind of emerged, that our analysis so far indicates, has come out, that I've called fight for a normal life. So within this, the mother refers to the forgotten child. So when the child can't go to school, for instance, mothers reported that they weren't getting support, sufficient support from school. One mother reported that her child was off for four weeks before the school even contacted her to ask where her child was. And then when the child goes back to school, the mother reported that there wasn't sufficient support, the child was almost sometimes left to catch up by themselves. There wasn't sufficient support in place to help the child merge back into normal life at school and be part of the school. So this was kind of the bigger theme, the bigger injustice was around the mothers' fight to give the child a normal life.

And there's also kind of themes around the child's perspective. The parent's view of the impact of the pain on the child in relation to the fact that their child couldn't do things. The child couldn't go to a social club necessarily, because some organisation wouldn't take responsibility for a child with a chronic illness, so the child couldn't go, couldn't take responsibility for the management of the child's condition. So there were issues attached to that, so the child would be excluded from engaging with friends, participating in normal life and other activities. And the child also found it difficult and started to feel kind of alienated too, within that.

Evans: I think this will resonate with many parents or carers of children with chronic pain issues. But how would you envisage your research being used?

McParland: To our knowledge, this is the first investigation of its kind, working with parents who have a child with chronic pain. We plan to take this forward to help us to design studies that will help us to understand the impact of parental appraisals of injustice on the child's pain outcomes such as the child's pain behaviour. We're in the very early stages of kind of starting to think about this and understand these processes. But this is the first point hopefully that will lead to in subsequent research in this area.

Evans: That's Dr Jo McParland, Senior Lecturer in Psychology at Glasgow Caledonian University.

I'll just remind you that whilst we in Pain Concern believe the 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, your circumstances and therefore the appropriate action to take on your behalf.

Don't forget that you can download all editions of **Airing Pain** from Pain Concern's website which is painconcern.org.uk or from Pain Concern's YouTube channel, just put Pain Concern and YouTube into your search engine, or from Pain Concern's Facebook site. I'll leave you with primary care pharmacist Sarah Long on the benefits of having a medicines review.

Long: Some people are very aware of what each medication does, and they perhaps tweak it, depending on how they feel. Whereas at the other extremes, people have forgotten why they're taking medication. So they welcome having a discussion about medication and perhaps are made aware that some of the effects that they're having or some of the symptoms that they're displaying, could well be due to the side effects of the medication, or indeed that they've got a particular condition that's exacerbated by certain of the medication. So generally, people are very pleased to discuss medication and link perhaps what they're feeling to the medication and to know that there can be some tweaks made.

Evans: Just use your pharmacist.

Long: Yes, use your pharmacist.

Contributors:

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