

Airing Pain Programme 78: Putting children's pain in the picture

How children can express their pain in art, plus tips for parents.

'In hospital. Don't know what's going to happen to me.' These words, written by a child asked to describe her pain after surgery, speak of the anxiety caused by a failure to reassure and explain.

This edition of Airing Pain focuses on the communication challenges faced by children and those caring for them. Producer Paul Evans hears from Alyson Twycross and Bernie Carter – both are nurses and academics specialising in children's pain – about how these barriers can be overcome using art produced by the children to represent their pain and its effect on them.

Alyson Twycross explains why it's important for children to be informed and involved in decisions about their care. She also gives tips for parents on helping children recover from surgery and minimise the risk of developing post-surgical pain.

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

Alyson Twycross: When I walk round the ward and see my students, staff nurses would say to me 'ugh, having the parents here, they make the child worse'.

Bernie Carter: However kind and nice and lovely you might try to be, you're still an adult and there's always going to be that power differential between yourself as an adult and a child.

Twycross: We need to educate the parents about the most appropriate way of helping their child cope with painful procedures, because if we've not been doing it and they then go

'there, there child, don't worry', then that shoots the child's anxiety up. And, actually, telling someone not to worry perhaps suggests there's something to worry about.

Evans: How do children – patients – and adult health professionals communicate with each other when their worlds are generations apart? In the previous edition of *Airing Pain* I met Zara and Amy, two teenagers in their GCSE years, both living with painful forms of arthritis. They'd been telling delegates at the Northern Ireland pain summit about how their conditions affect their daily lives and in this edition, I want to pick up on something they said about explaining their pain to other people, contemporaries and adults, starting with Amy.

Amy: You find yourself telling the same explanation to everyone. So when people say 'Why do you have a lift pass or why are you limping?' And you tell them you have arthritis, there are two responses: either, 'what's arthritis?' 'or my family member has that'.

So it's kind of the same story over and over again, but I think that once you tell your close friends, everybody else kind of gets into that 'Well, she has arthritis, everybody knows that'. Whereas, when I started first year two years ago, I had to tell a whole different year of people that I had arthritis. And there are still people in my year now that still don't know, but when they ask I'm not offended or angry, I'd rather they ask than be confused, which – I think a lot of people are afraid to ask because they don't want to offend you. But it's really not offensive because I've had this illness for five years and it's just kind of a part of my life that I'm okay with, so they should be okay with it too really.

Zara: Even though we're still quite young we don't act in the way children would when it comes to it, you know if we have a problem, we'll tell the doctor, we won't ignore it and hope for the best [laughs].

Amy: I don't like it when things are sugar coated when you go to the hospital, which they aren't usually, the hospital are very good with things like that. They're very good, they tell it like it is. But when people sort of dance around the subject of your disability, it's more annoying for us than upsetting because you just want to get to the point. If you have a question ask it and if you want to know something, ask it and if you want to say something, say it, we won't get offended unless it is offensive, so I think that's the big thing.

Zara: Uh hum, yeah, definitely.

Evans: So Amy and Zara, both in their mid-teens have the maturity and confidence to engage with their contemporaries and healthcare professionals about their conditions. They don't like it when things are sugar coated but if they have a problem they *will* tell the doctor.

Now describing one's pain is difficult enough for adults, but for children younger and less confident than Zara and Amy, being interviewed by doctors and nurses in a hospital or clinic situation can pose significant communication issues on both sides. Alyson Twycross is head of department for children's nursing at London's Southbank University. She also does research in children's pain management with children, young people and parents. And she faces the same issue in her research as any health professional would in a consultation.

Twycross: One of the issues with the interviews with post-operative children, who were 48 hours' post-surgery, was that I had to have a variety of different methods because some of the children had surgery on their jaw and they weren't very keen on speaking to me. I got them to write the answers instead and with the younger children, I used the draw and write technique, which is where you get them to draw a picture and write a few words down and then you talk to them about their picture.

Evans: So, if I were a child, it's getting a visual representation of my pain.

Twycross: Yep, how it feels to you. One of the things about pictures is that you often get different data to what you might expect. Like one of the pictures I got – and, actually, only two of the children did the draw and write technique and one child clearly didn't understand the question, so I didn't use that in my data analysis – but the girl that did draw a picture wrote on it 'In hospital, don't know what's going to happen to me', which suggested to me that she hadn't been prepared for her surgery and that wasn't something I thought would come out of my data. And if I'd just been asking her questions about her pain after surgery, I perhaps wouldn't have got that information about the fact that she was anxious or worried because she didn't... no one had told her what was going to happen properly.

Evans: Actually, it sounds really scary to me.

Twycross: If we're facing new situations and we know a little bit about what's going to happen, it's far less scary than just being told that you're having something done to you. And, actually, [excitedly] I had a crown done on my tooth a couple of years ago and I meant to tell my dentist at the time, that he should have given me better information because I had no idea I was going to have a temporary crown and what it was going to involve, I kind of just blithely turned up at the dentist. That really illustrated to me the need for information so you can prepare yourself for what's going to happen.

Evans: Dealing with children is obviously vastly different from dealing with adults. How do you get them to explain what's going on in their minds, their pain and things like that?

Twycross: I've got nieces and nephews who range from fourteen down to nine months and, obviously, when I'm talking to them, I'm talking in a slightly different way to the fourteen-year-old than the six-year-old. But the six-year-old, you can have a proper conversation with them, but you have to use words that are within their vocabulary and understanding.

Evan: It's not talking down to a child, it's talking at their level.

Twycross: Yep. I think it's really important not to talk down to them, sometimes adults can appear quite patronising. One of the things I've been quite good at is talking to children at the right level. I'm the eldest of five children so maybe that helps but I do sometimes see adults change how they're talking when they're talking to a kid. And I kind of think that's insulting. I don't know what children think, but they must notice that some people talk to them as if they're a normal human being and other people appear to be a little bit patronising and maybe talk down to them.

I educate, at the minute, just over 250 student nurses a year here in my department and they're training to be children's nurses and one of the things they do is about communicating to children, young people and parents. And they need to know how to communicate with children at different levels of development, different ages, children with cognitive impairments. They need to be able to communicate with children of two, five, eleven, sixteen. There are challenges at sixteen as well as at two.

Evans: I know [in a low voice]!

Twycross: [Laughs] And also – you've clearly got teenagers or are involved with teenagers [laughs] – and also talk to parents and actually, parents have differing needs as well and understand more or less about what's going on, depending on their experience and education, I guess.

Evans: Do you talk to children with their parents or without their parents?

Twycross: For research purposes, there is a huge... a growing body of evidence – probably not huge – about the pros and cons of having parents there. I usually give children the choice. The study I was talking about, which I undertook in Canada when I was on a sabbatical there a few years ago, the parents were all there. And I think maybe in the hospital setting, that's not so much an issue but I know that some of my colleagues, who have interviewed children in their own home, when the parents have been there and the brother and the sister have been there, there's kind of been a bit of interference 'no, no, no, no – that's not really what you mean'.

And, actually, one of my PHD students was interviewing a child about their pain and asked the child how much pain they were in and he said 'five out of ten', and his mum pipes up 'no, no, no, no – it's a two out of ten', and then he went 'yeah, yeah, yeah, two out of ten'. So I may have shot myself in the foot about my argument because that was in hospital. But I think there are pros and cons and you need to be aware that the child might feel more comfortable if the parents are there, but are they going to butt in and influence the child's responses and I guess you've always got to have that at the back of your mind.

Evans: One of the things that, as a parent and a grandparent as well, is that I can remember taking my son as a four-year-old to the hospital because he had knocked himself out. And he'd had a row for doing it [Twycross laughs] which made me feel really good. I was more emotionally battered by it than he was and I just wonder if it's a good thing to have a parent around sometimes.

Twycross: It's interesting, I think we do need parents to be there in hospital with the children, because I think it does help the children. I remember when I started my first placement in paediatrics when I was a student in the mid-eighties, parents were allowed to stay overnight. And then when I became a staff nurse on the same ward there was a new sister and we had parents on camp beds, so it was a bit of a nightmare climbing over beds to give IV [intravenous] antibiotics in the middle of the night or to see to a child but I think children are better, and the research evidence supports that. But we also need to reflect on how having a parent there impacts on how the child behaves.

We know for example that in relation to procedural pain, like painful procedures, that if the parent goes 'there, there, don't worry', we now know that that makes the child more anxious. And so, if the parents are going to be involved with the child's care, we need to educate them about the best way of reassuring their children. There's some research from the US and Canada, where they've actually trained parents to use the right kind of words before the painful procedure. And the child's had far less pain during the painful procedure and been far more settled.

So having parents is a good thing. Finding out about this research in Canada and the US solved a bit of a problem for me because when I walked around the wards to see my students in some of my previous jobs, staff nurses would say to me 'having the parents here, they make the child worse'. And, actually, knowing that we need to educate the parents about the most appropriate way of helping their child cope with painful procedures, explains that, because if we've not been doing that and they then go 'there, there dear, don't worry', that then shoots the child's anxiety up.

Evans: That's really interesting because my mum was a nurse and she would say having a parent anywhere near a child in hospital – this new-fangled thought that having mum and dad staying with the child – keep them away, they're only interfering. What you're saying now – correct me if I'm wrong – is that sometimes, if I as parent went and gave my child a huge cuddle, what I would think as a supportive cuddle, it's actually telling the child [in a low voice worried voice] 'Oh, this is going to hurt'.

Twycross: And actually, telling somebody not to worry perhaps suggests that there is something to worry about. We know developmentally and psychologically that having parents there is a good thing. I'm just doing some sociology of childhood modules and I'm trying to use those modules to understand why we don't manage pain as well as we could in children.

And I think one of the issues is that if you look at the literature about healthcare consultations, medics and nurses to an extent, will defer to the parents, rather than asking the child. I'm not advocating that we don't have parents there, but we actually have to be sure that we involve children in decisions, even young children. That we talk to them about what they want, as well as talking to the parents and don't assume that the children are not competent to be involved in decision making.

Evans: How do you teach your nurses to speak to parents?

Twycross: They have various scenarios. One of the things I used to do in one of my previous organisation which I really liked, in the first year they did a snapshot and it was focusing on communication. There were three or four different people they had to communicate with, so a parent, a child, an adolescent. By the end of their first year, there was jargon they had picked up and we'd do a trial run and we'd go 'Do you really think the parents or child are going to understand that?' So I actually quite like that model of assessing them in a skills lab situation so that they can practice their communication and get some feedback in a safe environment. Because if we get the communication right about all aspects of healthcare, children and parents are going to have a much better healthcare experience and it would be less frustrating for the nurses.

One of the things I've used in cancer care is setting a pain goal. So they decide at the beginning of their child's admission to hospital for example, what they want the pain level to be so, two out of ten, three out of ten, whatever, and then they build the pain management plan around that. What I think is great about that is it starts the communication with the parent and the child and the nurse about what they want the pain to be, what pain level they want the child to be at.

We're not always very good at doing that. In my research, when nurses have communicated with parents, my research in the UK suggested it was when professional middle class parents ask questions about the pain, the nurses would then respond, if the parents didn't ask questions, the nurses didn't discuss the pain. In Canada the nurses did talk to the parents but they focused on what pain medications *they* were going to give. There was no 'Let us know if your child's in pain, let us know if the pain medications don't work'.

So it's more, I think we need to have an open dialogue, but we need to reinforce it as well. It's almost like we need to have posters on the wall saying 'We don't want your child to suffer unnecessary pain'. And address that public misconception that just because you've had surgery, you are going to have moderate to severe pain. Particularly as there is emerging evidence that if you have mismanaged acute post-operative pain, severe pain for a number of days, you are more likely to get chronic post-operative pain, even in children and that's a significant proportion of children getting it. The first study found that 15 per cent of children got chronic post-operative pain. We are beginning to understand the risk factors, so we should be addressing them and one of those is making sure children are not in severe pain, for prolonged periods post-operatively.

Evans: That was Alyson Twycross, Head of Department for Children's Nursing at London Southbank University.

Now, 15 per cent of children getting chronic post-operative pain, is a startling statistic, especially if something as basic as good age-appropriate communication skills could help reduce those numbers. So what should we as adults know about talking to children? Bernie Carter is professor of nursing at the University of Central Lancashire and she also works at Alder Hey Children's NHS Foundation Trust in Liverpool.

Carter: I would use stories, so I would get children to perhaps tell me a story about their pain or if that's going to be too difficult for them, because the pain is too close to them, is too sensitive for them to talk about specifically, perhaps get them to tell us about another child in pain, so they express it through that.

One of the other ways that I use, that I think can be really successful and the children really quite enjoy, is using art space methods. So that can be as simple as giving a child a piece of A4 paper and a pencil or you can give children a whole range of different crayons and felt tip pens with a load of colours they can use. You can use collage, so you can give them a range of different materials to use such as, bandages and wool, raffia and paper, glue. Materials that have got a different feel to them, like foil, stuff that crinkles, to try and get a whole range of different senses that they can actually portray.

And then we either use sketchily drawn body outlines that are not like the body outlines you can get on a standard pain assessment chart. You put them on something like A3 paper and then give the children the chance to actually build something up – a visual picture, a 3D picture of what their pain's like. Or you can give them a plain piece of paper and say something like 'Tell me what your pain's like, draw it' use these materials. Sometimes you can work with them if they want a bit of support, but mostly what we do is just leave it to them to make the decisions as to what materials they'll use.

Evans: It's one thing for a child to do that but you have to be able to interpret that as well.

Carter: There are ways that you can do to do an interpretation of that, looking at the materials used, the choice of materials, the depth of materials used, the colours they've used, the amount of the area that has been covered, how they have actually engaged with the activity. A simple thing, if they are colouring something in, whether they are colouring it in very lightly or they are colouring it in like billy-oh and really scribbling and getting indentations of the colouring in into the paper.

And those are all interesting ways of working, but, for me, the more important thing is using that art space approach, that picture they've created, they own, that expresses their pain and getting them to start to talk about it. So 'what's going on here?' 'tell me what's happening here'. And in little words they can then start to take you on the journey, to show what's happening and where things are going wrong for them with their pain and what they want to do about it. So you can get them to talk about which is the most important pain, which is the one they don't like, which is the one they've got most power over, which one they'd like to zap first and that way you can start to get a sense of what's really important to them.

So for me, their meaning and their interpretation is more important than anything that I as a researcher can actually apply from outside because that's coming from their world of meaning as a child, rather than my interpretation as an adult with all the expectations that I have. So, for example, one of the studies that we've done children used plasters, so we had quite a lot of these little body outlines covered in lots of plasters and we were trying to work out what was going on and the plasters were denoting the intensity and perceived severity of the pain, rather than the fact that there was a need for a plaster or the skin had been broken and there was blood. So a plaster for the children under the age of about nine, meant it was a bad pain. So if we had interpreted it from the outside, we'd have thought there'd have been an injury and there hadn't actually been an injury in that particular situation. So there again, it was like a figurative use of the materials.

Evans: Thinking about my children and now my grandchildren, who are six and three, when they get involved in their artwork, they live in a completely – not an isolated world – but they really get stuck into it. And to work out those thought processes of why they're doing such a thing, there's a tremendous resource there that adults don't have to describe their pain.

Carter: Although if you give adults art materials, they can do some really fantastic work in expressing pain and it can be a way of unlocking an experience that they've not been able to express in words. So for some of the parents of children with chronic pain, who have to live alongside the child's chronic pain and can feel overwhelmed, desperate and anxious and guilty and a whole range of different emotions as well as feeling very stressed by the care they are having to provide. There are studies that have shown the therapeutic use of artwork for parents. And when you look at adult drawings of pain, there's resonances that run all the way through so the same sorts of imagery are used, so jagged lined, red colours, things that are seen to be threats, so hammers and hard objects, things that are crashing, so those images are pretty resonant within children's work as well as within parents' and adult sufferers' work.

Evans: I was asked to describe my pain recently and it took me a little bit unawares. And the way I described it was – it's a sort of general, all-over aching – being enveloped in a beige or grey jelly. Now, actually, being put on the spot and having to think in that way and to describe it to somebody else, I found quite good.

Carter: Yes, I believe children have got a really strong sense of agency and I believe they've got a lot of competence and capacity, but sometimes using words can be quite tricky. So when we are using drawings or artwork or collage work or sculpture or whatever, the artwork gives the children a chance to pause and take stock of stuff and then start their drawing. So where perhaps, you were asked what your pain was like, there would have been, possibly not more than a 10 second pause before you felt you had to give an answer because that's what's socially polite to do.

Evans: We don't like silence.

Carter: We don't like silence. There's an acceptance with drawing that there can be silence, which means that if perhaps you're asking a child to draw some of their pains or draw a picture of what they're life is like having pain, it's acceptable to say 'We're going to give you 15 minutes or we're going to give you 10 minutes to do this and you start whenever you want'. And they can start to do this and they actually map out those sorts of things that they want to talk about. So I would then do my interview based on those images that they had actually drawn, rather than me asking questions that come from my frame of reference.

And quite often you'll see in the drawings of children and adults, that there's a notion of envelopment that's keeping them away from the world where other people can't get in because they don't understand their pain or it's a fog or a blackness that has kind of got over them. So there are these notions of boundaries that you can see. And the responsible person, if you are being responsible when you are talking to somebody about that, you wouldn't say 'oh I can see you're in a bounded area of grey jelly', you'd say 'tell me what you're telling me, tell me, what's this picture telling me?'

You have to go a bit carefully with the little kids because they generally expect that you know exactly what. You have to try and work out if it's up the right way perhaps, but it's just a device it's a trigger to get people to be able to talk. I think it's Goffman that talks about drawings being a ticket to ride somewhere else, so it gives you permission to actually go in. So it's a very patient-centred way of working.

Evans: I wonder also is it a way of taking the focus away from the child and putting a third person in the painting that you can both relate to?

Carter: One of the things you have to think about when you're interviewing children or working with children is that however kind and nice and lovely you might try to be, you're still an adult and there's always going to be that power differential between yourself as an adult and as a child. And one of the things that artwork can do is mediate that a bit, so instead of me looking politely and directly into the eyes of the child and asking them to tell me something, they can actually talk.

Quite often a lot of my conversations with children are undertaken to the top of the head because they're still busy drawing, so in that sense it can become like a third actor in the room that becomes a voice for children. Sometimes the children and the parents can be quite surprised by what the child has drawn.

The way that we normally try and express pain is that we use words and words can be powerful but they can also be quite dismissible as well. If a child actually presents you with an image of what their pain is like and it's black and it's sad and it's destroyed and you can see how far the red is over the page, in terms of where the pain goes and that's said in conjunction with 'this is what it feels like to be me', it's really difficult for people to ignore that, because we are kind of hardwired for these visual images to kind of take notice of that. So I think it can actually give children that sense of validation that they have communicated effectively and people have taken notice of that.

So people will use artwork within chronic pain clinics as a starting point, so instead of starting a conversation with children from a clinical history point of view, the clinical conversation can start from 'this is what it's like to be me...' 'so, tell me about your picture'. So it becomes a really strong voice that can be filed in the children's notes. And as children's pain improves and they develop even more mastery over their pain, or interventions become more effective, their subsequent drawings are likely to act as indicators of progress as well. And that can be useful because sometime your progress might be slow but your drawing actually looks less painful, so you can use that to track children's progress over a period of time.

Evans: That was Bernie Carter, Professor of Children's Nursing at the University of Central Lancashire.

I'll just remind you, as always, that whilst we at 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* professional on any matter related to your health and wellbeing. He or she is the only person who knows you, your circumstances and therefore the appropriate action to take on your behalf.

Now, we heard earlier how the mismanagement of acute post-operative pain, that is severe pain for a number of days following an operation, adults and children are more likely to get post-operative chronic pain. So, what advice should be given to parents of a child going in for an operation. Alyson Twycross Head of Department for Children's Nursing at London Southbank University

Twycross: I would want the parent to understand that the child doesn't have to be in pain after surgery, because there appears to be a general acceptance among parents – and the general public as a whole – that because you're in hospital and had surgery, you're inevitably going to have moderate to severe pain. Whereas, actually, that isn't the case.

And because parents appear to have this misconception, they seem to think that if the nurses could do anything, they would have done it. I've had children and parents say that to me in the past and because they believe some pain is to be expected, they don't go to the nurse and say 'Hey, look, these pain medications aren't working. Can we increase the dose? Can we try something else? Can we use some of the non-drug methods?' The way to change practices and to make sure children don't experience unrelieved moderate to severe pain in hospital is to enhance parent power.

One of the issues though, is that now that a lot of the children have day surgery, they're home within 24 hours, so it's the parents themselves who are managing the child's pain. And if they're not educated and hold misconceptions and erroneous beliefs about how children behave in pain.... A lot of parents think – as nurses do too – that a child's behavioural cue is indicative of the pain they are in and we know that's not true. A lot of parents think pain medications are addictive and have horrendous side effects, for most pain medications, that's not true.

So, parents when they are with their child in hospital post-operatively need to advocate for their child. And that can be quite difficult, because there are power relationships, but I think we need to find a way of empowering parents to advocate for their child's pain and jump up and down when their child's pain isn't relieved. I think pain should be no more than three out of ten, in the immediate post-operative period. And then when parents are taking their children home they need resources. We also know that parents often have to ring another healthcare professional for advice, usually in the middle of the night, and so I think we need to think of different ways of empowering parents when they are managing their children's pain at home.

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