

Airing Pain Programme 103: Pain and Relationships

How pain's unpredictability can affect interpersonal relationships, and recognising help when it appears.

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With between one third and one half of people living with chronic pain in the UK alone, the number of people experiencing the effects of pain explodes when considering family and friendships. For some of these people, life can become a cycle of hospital visits, blood tests, and scans. So, what can be done to ease these relationships?*

In this edition of Airing Pain, Paul Evans and eminent psychotherapist Dr Barry Mason speak about their personal experiences with fibromyalgia and ankylosing spondylitis.

With many chronic pain conditions being "invisible", explaining your pain may seem impossible, and as the family's "uninvited guest", it can cause people to close up to those looking to help. Dr Mason explains that not speaking about this uncomfortable topic can lead to further issues, and how opening up can lead to better family teamwork.

* <http://bmjopen.bmj.com/content/6/6/e010364>

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 health care professionals. I'm Paul Evans, and this edition's been funded by the JTH Charitable Trust and the Persula Foundation.

Dr Barry Mason: When people are in pain I make a distinction between a primary relationship with pain, and a secondary relationship with pain. A primary relationship with pain is where pain tends to dominate your life. But it's not just that it may dominate the life of the person with the condition, it can also dominate the lives of those you are closest to. Pain is therefore in the foreground of their lives, and getting on with life tends to then be in the background. A secondary relationship with pain would be where getting on with life, for those with the condition and others close to you getting on with life is in the foreground of your life, and the pain, although there, you manage to keep in the background.

Evans: In a lecture to the Institute of Family Therapy in 2016, the eminent family psychotherapist Dr. Barry Mason talked about his research into the effect of chronic pain on

significant relationships and conversely, the effect of those relationships on chronic pain. His recent research is on the management of fibromyalgia but in 1972 he was diagnosed with ankylosing spondylitis, that's an inflammatory condition that affects the joints of the spine. Now, it's important to say that in the interest of confidentiality certain clinical details have been changed in our conversation that follows, but it was his diagnosis of AS that inspired his initial research.

Mason: What I was told at that time, that it was a chronic condition--it would develop over time—that the impact it had on me was beyond just me. It was about, I'll lose my job, and of course it was affecting not only me, but it was having an impact on my personal relationships, how I was, and sometimes I dealt with it by going into myself, which is not unusual with people with chronic pain conditions. That was the way you coped with difficult times. And so I was very aware, not just of what was going on with me, but also about how other people were relating to me, and that in itself affected how I managed my condition.

Evans: Because they talk about pain as the uninvited, unwelcome guest into the family, don't they? It impacts on absolutely everybody, all relationships.

Mason: Yes, close relationships you have, work relationships. Coping, keeping going. And sometimes you have bad episodes and the pain is worse than other times. One of the words I think fits very well for chronic pain conditions is that it's unpredictable, that it's there sometimes, then all of a sudden it's not.

I always remember for quite a while having continuous pain, and then I had a remission, and I remember thinking I always knew there was a state of being pain free, but I've only just re-experienced the distinction between being pain free and having pain. And of course then you think, perhaps it's over, perhaps that's it. And of course it wasn't, it comes back.

And I started also to, as a way of people not asking me too much about, how's your back Barry?, because after a while it can actually get a bit boring, but they were concerned, and then to help people not get into that I actually found myself wearing suits and looking smarter in the hope that people would, this is pathetic in a way—I laugh at it now, that people would think, oh, he looks good. And it was all about the physical appearance, because you know, you show it in your face at times, as you know. And you try to not do that, but it's very hard at times.

Evans: In my own experience, I have fibromyalgia, one of the worst things that people can say to you is, how are you today?

Mason: The danger is, on the one hand there is a wish for them to be concerned, genuinely concerned, but it rather fixes you as a person with a condition. It feels at times as though you are the condition, rather than a person with a condition. I remember saying, it's like I'm not Barry, I'm Barry the back.

Also, I'll stress that people are genuinely very concerned about you, so how do you manage that concern without getting fed up with the concern, if you see what I mean, does that make sense?

Evans: It does, but many people feel that if they tell the truth all the time about their pain, people will stop asking. We don't want to come across as miseries.

Mason: Yes, well that's the difficulty, that they would say how's your back? And I would say it's fine, when it wasn't. But then they might pick up that it probably wasn't fine, and be left with, should I take this further or not. It's almost like it was a pattern, they were trying to be concerned and you were trying to deflect.

Evans: And the other thing about that, it might be cynical of me to say it, is that when somebody says how are you, they don't really want an answer, it's a politeness.

Mason: It's a politeness yes, and like you'd say to anybody.

Evans: So how did your relationship change when the ankylosing spondylitis started?

Mason: This was 1972. I came out when I was told by the rheumatologist, and I sat outside the consulting room, and I got really down, and I said this is terrible. And I went away to the library and got a book, and it said, well you can just bend over and sometimes it can kill you. Rather dramatically I thought, oh well I'll probably last till I'm 35. It was all rather dramatic. And the other thing was, that well I'll just have to get on with it, as that's how I dealt with things anyway.

And my relationships in some ways didn't change that much, because being a person who got on with things was how people knew me to be. But at times of course the pain was quite bad.

Evans: How did your wife's relationship with you change? You have the pain, but she has to deal with a different you in many ways.

Mason: Yes, the fact that I'm an individual with a pain condition, but that pain condition has particular effects on me. The pain draws you in, if you withdraw, what do people close to you do? And that's one of the things also that people often don't get into. Certainly in my research around people with fibromyalgia one of the issues that came up was people not being sure, let's say there's a person with fibromyalgia, the partner, say, wasn't very sure about, well, should I ask you whether you want help, or should I wait for you to ask me. Because the person with the condition usually wants to maintain their independence. For some people with the condition, maintaining independence means I will ask you if I need help. Other people would see it in a different way, and say I would prefer you to ask if you think I need help. What I found was that, that never gets talked about. So when I've seen people I've checked out with them: when you need help do you want your partner or family member to volunteer, or would you prefer them to wait and you ask them? That can be very difficult; if you get it wrong it can create tension.

Evans: It's quite interesting because me, and possible other people with fibromyalgia and other long term conditions, we want to be in control of it ourselves, but actually we do want somebody to be passive, passively look after us, although we're in control.

Mason: Yes. One of the questions I do ask people who have a chronic pain condition is, how easy or difficult is it for you to not do things as well as you used to do them, because sometimes people force themselves to be like they were before, of course that can be worse. And then I might ask somebody in the family, how difficult is it for you to say to your partner, or your father, or whoever: look you're overdoing it. And are those things talked about, or are they thought, well they're almost not conscious of those issues that might be useful for discussion.

Evans: What quite often happens with me and my wife is that I will be going downhill, and getting more and more difficult to live with. And she will say, Paul you're in trouble now, stop. And it's like there's a traffic light saying you can stop and start again, we know where we are, we've flagged up where you are and we can start again.

Mason: What's interesting to me is then, what's the story of how she felt able to do that with you, and you being able to find that useful. So there must have been something that was

around, either because you know each other, as to, at that point she said, well I'm going to come in here and you finding that useful.

Evans: Often it's an argument, and you had to draw the line and say, this is why we're arguing, it's because you don't feel very well.

Mason: And then it depends, to some extent, on the history of your relationship just doesn't exist in isolation. You are presumably acknowledging that your wife has some expertise in helping you.

Evans: Absolutely, she can see me better than I can see myself.

Mason: Because you know you can't see the forest for the trees, and when you have a bad episode it's like you're on a zoom lens and you can't take it out onto a wide angle lens and see the broader picture.

But it is about being, are we open to being challenged about how we're coping with our condition. You have to have that idea of, I've got my own views about how I should handle this, but I also need to be open to that idea that somebody else could come up with a useful idea about how I should handle this at this point

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Evans: You're not an island, you are a unit, that works as a unit.

Mason: Although I think it's also important to add that you get people who have a chronic pain condition who are on their own, they live on their own, but they have friends. So it's still 'family', it's relationships: how do our relationships help us, or constrain us, in how we manage our condition.

I think that what I try to do is help people talk about what they haven't been talking about. So I can remember a situation where I worked with a couple, and they were in their sixties. The woman had a long standing chronic pain condition, about 25 years, had been to a pain management clinic. The husband was very supportive in concrete ways, but she said that he wasn't very good in terms of talking about how she was feeling. And he came with her to the appointment, and he was a bit reluctant to get into it, he was there for her.

Anyway as their session went along I thought there was an elephant in the room, and the elephant, because she'd also had a triple heart bypass, the elephant was his fear of her

dying. And I thought for about ten minutes, should I go into this or not, it's the first session. Anyway I decided to take the risk of doing it, and I rather overdid it, it's rather embarrassing to say. But I said to him, do you have a worry that your wife is going to have another heart attack, stop breathing, drop dead. It was rather over the top, and he didn't bat an eyelid, he said no, I think about it all the time. It was the first time he'd said it, and it went on, and I said at one point, how come you haven't said this, and he said, well, if you say it to somebody else you give it to somebody else. And I thought that's very interesting.

And when we went into it, when he was growing up he had a three year old brother that died when he was four. His father died a few years later, and he had a sister who died a few years after that. He'd grown up with this idea that how you cope with difficult times in life, is you just get on with it. She'd grown up in a family where you talk about things. So what they'd begun to see was that there was a logic as to how each of them behaved, based on their experiences from a fairly early age. She saw the logic of why he didn't want to talk about things, and he saw the logic of why she did want to talk about things. This came out after about 40 years together, never said it before, never realised it.

When the work finished, they got on much better after this, and I saw them for about six, seven sessions, and at the end of the work I said, what's come out of this for you? And he said-- it was like a language of another generation-- he said, I've realised one thing, the women, they like you to talk. It was a sort of beautiful moment, and I saw out the corner of my eyes his wife beaming.

But it was also based on a question I ask of people, which is related to the work I do as a therapist, try and get a picture of what was happening when they were growing up, about the messages they picked up about how to cope with difficult times. Because all of us grow up and I think we pick up messages; in my family I picked up that you just get on with things. So I ask this question: when we're growing up in our families, communities, we pick up messages about how to cope with difficult times in life. What were the messages you picked up when you were growing up? And he said well, you've just got to get on with things, and she said well, talk about things. And then people can see there is a logic to their differences, not an illogicality. And it's a question you don't get normally asked, you don't go to the supermarket, and you see a friend, and you go over to the friend by the vegetables, and you say how have things been, they don't tend to say, well you know I've been thinking about my patterns in coping with adversity. And you're probably unlikely to say, you know I've been thinking the same thing. My job is to come at things from a different angle, and how do I help

take people off autopilot, so they become curious about their own process that they're going through.

Evans: I presume in a situation like that, he who keeps everything to himself, and she who wants to talk about everything, do you come to a point in the middle or do they skew to one side?

Mason: I take the view that there are different ways of seeing things, that's what we do. So people come and they may have a fixed view, that this is how I see it, and it may be that they think there is no other way of seeing it except this. So what I try to do is not to force a view on them, but to try and work with them in such a way so they, in a way, start to think there are other ways of seeing this. Because the act of speaking is the act of hearing yourself speak, you speak and you have a relationship with what you hear yourself say.

Like I said to that man when he clearly said, I've never said this before, I said to him, what's it like hearing yourself say that? And he said it's a relief, I'm glad I said it in front of my wife. When I asked her, what's it like for you hearing this? She indicated it was really good. I remember her saying, I didn't know he cared. So she had the idea that he cared, it wasn't that he didn't care, it's just that his view of how he should cope with difficult times clashed with hers. But then it came out, and then they could see.

Evans: In my own background, my mother refused to let pain get in the way of everything. Even to the point of her having lung cancer, and being in excruciating pain, she was fine. Now I think that had a tremendous effect on me and the children. First it was very damaging that she wouldn't tell us she was ill in the first place. But I never use the word 'pain' with my doctors. Are you in pain? No, no, I ache. Well, aching is pain. But it does have a really, sort of, what you're brought up to think about pain...

Mason: Yes, you put a meaning to it. And that's what people do. It's like when you say, what level of pain are you in, on a scale of naught to ten. And people will say, oh nine, well one person's nine is another person's six. It's very subjective.

But what you've just said then, is it's logical, that's the point. That what you said to the doctors was logical based on the story that you developed about yourself in relation to your mother. It may seem illogical, but I'm thinking about is, in what way is there a logical story to this view that this person has.

Evans: So why do people with chronic pain come to you in the first place? Surely that must be some sort of indication that they're accepting that there may be issues in the relationship.

Mason: What that question reminds me of is that for hundreds of years, in the history of managing or dealing with pain, it was just physiological. It was only in the 1960s that people started to see, based on a particular paper at that time, in 1965, that psychological as well as physiological, and how we dealt with pain was also to do with our relationship with it on an emotional level. From that you started to get psychologists involved, psychotherapists and other people. So one of the questions I usually ask and explore is, what's their view about coming to see someone like me.

I remember one person saying, I didn't want to come because they're obviously sending me to you because they think I'm mad. And I said no, I don't take that position. It's just that when people are in pain it has an effect not only on how they are physically, but how it effects on relationships. And sometimes talking about things may help.

There's a family I dealt with where the mother had severe chronic pain, and her way of coping with it was to grit her teeth and keep going, keep going. But what came out was-- because I asked about what's the effect on your children?-- there's a 15 year old daughter and they don't really talk about it, do they not talk about it because they're not worried about anything, or is that their way of dealing with it. And what happened was that eventually the daughter came out and said she was worried about the mother committing suicide. The mother said to her, how long have you been thinking that? And it turned out that it was five years she'd been thinking that, but kept it to herself. And the mother said, oh my god, you've been thinking that for five years and you've never said anything? And I said to the daughter, what's it like for you, saying that here? And she said, it's brilliant, brilliant.

So that's the effect that somebody's individual condition can have on the way pain, or whatever it is, is managed. So it all goes back to the relationships. Like with fibromyalgia, people not believing me, that I've got this condition. One, it helps to have a diagnosis, and two, people find it difficult with a condition like that to really explain to others what it is. I've had people say to me, it drives me mad, I don't know how to explain this. And I think that one of the things that is important is that professionals in the field, whatever they are, medics, psychologists, psychiatrists, psychotherapists, whatever, should help people with a condition like that to be able to talk about it and explain it to others. Because I think that by doing that, people are less likely to think that they are just putting it on. It frustrates people when they

can't say, this is what my condition is. So people just need some help. So here I'd say, OK a person at work asks you what it is, so how are you going to explain it, it's practising.

Evans: I want to go back to the mother and the 15 year old daughter, and the relief of the daughter being able to say openly, 'I'm afraid of you dying'. Did that stay just in the room, or did the openness carry on beyond the consultancy?

Mason: Yes, it was almost like it became less powerful, it wasn't so big. It was like if you wrote it on a piece of paper, 'Will my mum commit suicide', it was like a big S on a piece of paper, and what happened was it became a small s.

I suppose one of the things with the further work I did with them is just that taking the chance, talking about difficult things could be helpful. On the one hand, this mother, her way of dealing with things was to just get on with it. Now that can be very helpful, but it also at times can be not very helpful. And it reached a point where it tipped over into not being very helpful. So this coming out not only changed the relationship in terms of the mother and the daughter, it changed the relationship about talking about things in general, that when things were difficult it was OK to talk about it.

Actually the daughter, after the work finished, dropped me a postcard every so often, and said still ok, still ok. When that kind of thing happens you also get better teamwork, and teamwork is very important. So if there is the teamwork in the family, or the couple, and there's also the teamwork with the professionals. And that the person with the condition is part of that team, not separate from it. And in fact I still do it, and I encourage people to do it, when you go into a medical appointment write down on a piece of paper what you want to say and give it to them to read in front of you. Because you go there sometimes and you feel pressured because of time, you're anxious and then you forget what you want to say. And I still do it myself every appointment with my rheumatologist, I write something. It's a message that I'm part of the team.

The other thing that came out of my research is that medication is an individual issue, but it's also a relationship matter. We often have various medications we may be taking, and of course all these medications have side effects. Sometimes it'll be my stomach, and sometimes my fuzzy head. That then affects relationships, because if you are a bit fuzzy, the people who are close to you, do they know whether you're not with it because you're just not being very communicative, or do they know whether it's likely to be the medication? So it's

really important from a relational point of view that people who you live with are aware of the medication and what they may have to expect. It's not just the individual taking the pill.

Evans: That's family psychotherapist Dr. Barry Mason. And of course, as we said earlier, in the interest of confidentiality certain clinical details we talked about have been changed. And don't forget 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 wellbeing. He or she is the only person who knows you, your circumstances and therefore the appropriate action to take on your behalf.

Dr Barry Mason.

Mason: There's a lovely saying by the writer Hannah Arendt in a book she wrote in 1968. She called illness and difficult things, she called it an unbearable sequence of sheer happenings, where the weight of what you have to deal with almost prevents you from doing things. And I thought about that in relation to what people have to deal with when they have an illness. Blood tests, hospitals, scans, GP visits, the weariness of that, and often that gets forgotten. For some people it's like their social life is visiting the hospital. It's just taking that into account, that people are tired sometimes. Not just because of the effects of the medication, but just the weariness of dealing with it all.

Evans: Ground down by the process.

Mason: Yeah, ground down by the process.

Evans: It's fascinating that you talk about, a relationship not just with people. Everything in life is a relationship.

Mason: Exactly, spot on. If I see a chair, I don't just see a chair, I have a relationship with that chair, because I think, is that a good chair to sit on or not. So I'm having a relationship with it. Yeah, that's a perfect way of putting it, everything is a relationship.

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