Airing Pain programme 19: Family Therapy

How pain affects family members and how family therapy can help.

Pain can sometimes seem like an 'uninvited guest' or 'intruder' into family life. In this programme we look at the strain pain places on all personal relationships and how family therapy can help. Clinical psychologist Dr Elaine McWilliams talks about the impact of pain on the sexual and intimate side of a relationship, and she and family therapist Jan Parker also explain the effects of pain on the parent-child relationship. Psychiatrist Dr John Rolland explains how a 'resilience approach' can help families to move forward together.

Paul Evans: Hello and welcome to a new series of ***Airing Pain***, programmes brought to you by Pain Concern, the UK charity that provides information and support for those of us who live with pain. This edition has been enabled by a grant from Big Lottery Fund Awards for All, Scotland.

Dr John Rolland: The illness is an uninvited guest in the family.

Dr Elaine McWilliams: The sexual side of their relationship was incredibly important to them and this had started to break down and she actually felt that he didn't want her anymore and that she was no longer attractive because of the cancer.

Rolland: We have to deal with this person who came into our home which is what we call 'pain' and it puts it out there so that all of us are relating to the issue of the pain not just the person who is in physical pain, but it becomes something that everybody in the family has a relationship to this.

Jan Parker: And the conversation became – not about 'how to fix my naughty boy son' – it became about the impact of pain and fear on the family.

Rolland: Somebody corrected me – a patient once and said – 'You know, it's not really a guest I didn't invite them – this was an intruder – he broke into the house.' [Laughs]

Evans: Well guest or intruder – when chronic pain enters the home – it takes over everyone's life and not just that of the person in pain. But the way relationships are managed will have a huge bearing on who stays in control, the pain or the people.

So who can help put you rather than pain in the driving seat? Well earlier in the year, the Association for Family Therapy Scotland in association with NHS Education for Scotland

organised a two-day workshop under the heading ‘Family perspectives on illness and multi-stress challenges facilitating resilience and growth out of illness, crisis, trauma and loss’.

Jan Parker is a family therapist working in the NHS. She’s also Communications Officer for the Association for Family Therapy.

Parker: Family therapy is a way of working not just with the individual child, young person or adult who is experiencing difficulties in their lives but with *all* the people who are important to them. And that might be family members it may also be teachers, friends, whoever can help make a difference in their lives. And it’s actually a way of freeing up people’s strengths and building on their rich relationships that matter to them. It’s like a pebble in a pond, the patient’s the pebble going into the pond but the ripples go round and round and affect everybody in concentric circles and it has a huge impact on the family.

Evans: Dr Elaine McWilliams is a consultant clinical psychologist working with cancer patients in palliative care and…

Elaine McWilliams: From my own personal perspective – more recently I have become quite disabled – I look absolutely fine if you look at me now – you wouldn’t know – would you?

Evans: And you’re smiling!

McWilliams: And I’m smiling – you really wouldn’t know. I actually can walk about five minutes or stand for about five minutes and then I’m in agony. But I look absolutely fine.

Evans: So how does that impact on the way you feel?

McWilliams: I think it’s become part of who I am. I have good times and I have bad times. That’s the truth and my husband, we’ve been together now for 19 years.

Evans: And you’ve had the pain for 20 years.

McWilliams: For 20 years – yes. He knows when I’m struggling, he can tell by the way I move, I don’t say anything, I don’t complain but he can tell just by the way I’m moving that I’m in a lot more pain. But he would say that a lot of people wouldn’t pick up the subtle clues. And so, for example, we had a visit down in London recently and I wanted to go and visit the Natural History Museum and there was no way I could do that without loaning a wheelchair. And so I was pushed around for five hours in [laughs] a wheelchair and that was an interesting experience as well because part of me thinks that I feel a bit of a fraud because actually I can stand up and walk.

Evans: But that's the big thing – having the wheelchair is like putting a big badge on and saying…

McWilliams: Hmmm…I'm disabled! Yeah!

Evans: But how were you treated when you were in the wheelchair? Were you treated as you wanted to be treated?

McWilliams: I was treated very differently, very differently. I could almost tell that the look on some people's faces that they would look at me and think, 'well you look okay really – you don't look *ill – you don't look...*' And, of course, occasionally I would get out of the wheelchair and stand up and go to the toilet and then people would look at you and think that you are a bit of a phony really – aren't you?

Evans: 'This is a wind up.'

McWilliams: 'This is a wind up' – yeah! And a very interesting experience being on a different level to everybody else as well and people would occasionally bump into you, push into you, knock you – didn't see you.

Evans: So how does your own experience as someone living with chronic pain – how does that fall into your job?

McWilliams: Well I feel I've got a little bit of street-cred [laughs] really. I mean, not that I burden my patients and families that I work with, with what's going on for me. But I feel I have a level of understanding of what it's like to live with pain and what it's like to try and manage pain and still try to have some normality; still continue to do the things that you want to do; still enjoy family events. And I still want to host family events in my house, I want people to come, I want family to come, I want to feed them, entertain them… And I see that with my patients as well, they want to carry on – the families want to carry on as normal as possible.

Evans: But it's not just the events, is it, you talk about wanting to pick up your three-year-old child.

McWilliams: Yes.

Evans: Well okay there's the physical thing that you find it difficult, but there's the *guilt.*

McWilliams: Yes absolutely! If we go to the park I feel like I should be running around with him and after, say, well five minutes at the moment, I go down on my haunches – that gives me some relief and I pretend I'm looking for something in my bag because I don't want to

stand out. I don't want to look unusual in the playground compared to other mums and so I'll sort of ferret around in my bag, pretending … you know to just get a little bit of relief.

I see families – I see that in them as well, the guilt that they can't do the things that they would like to do with maybe younger children, adolescents as well. And grown up children, where they would like to be involved in grandparenting.

Evans: As a psychologist, how do you help them through this?

McWilliams: I listen to their story and to the family's story, it's really important for me to try and understand everybody's story in the family because it will all be slightly different and hopefully when I'm working with families where they may be struggling, they may be in crisis – what I hope to do is to put all those stories together so that as a family they have a coherent story they have a shared story, shared narrative.

Evans: Because going through, let's say a standard nuclear family, a couple, he has chronic pain and he is going through cancer treatment, pain from the cancer, misery from the treatment, there's the wife trying to cope with her own emotions.

McWilliams: And she's terrified, she's absolutely terrified but she doesn't want to show that maybe. She wants to protect him and he's trying to protect her and them both trying to protect the children and everybody's… and everybody's [laughs] trying to protect everybody else. And nobody's able to speak. And what I suppose I try to do is help them to speak – to find a voice to share. Maybe not everything because, you know, we are entitled to keep some things but some things are not spoken about, because people are trying to protect each other.

Evans: Dr Elaine McWilliams. You're listening to ***Airing Pain***, the programme brought to you by Pain Concern, the UK Charity that provides information and support for those of us who live with pain. Now whilst we 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.

Now today we're talking about relationship issues surrounding chronic pain and a key speaker at the Association for Family Therapy Scotland workshop, was Dr John Rolland, he's a physician and family psychiatrist at the University of Chicago. He's also Co-Director for the Chicago Centre for Family Health. He adopts what he calls a resilience approach:

Rolland: Resilience is the – we don't just think of it as bouncing back from something which means trying to stay where you are but to get back, but actually bouncing forward. How can you actually become stronger than you were before the illness? You come to observe more the preciousness of life, so again, some people, I'm interested in how some people develop this ability or have this ability and our work is to help families sort of draw on their resources.

Evans: So maybe at the start of somebody developing chronic pain in a standard family, say, husband, wife, two children, then there are four people with completely different outlooks on what is happening to that unit. And, firstly, there's the husband who has the pain – well, let's say it's the wife, who has the pain – the husband may go into himself, thinking – how do I cope with what is going on? He'll have his own anger, she may have guilt over not being able to cook or work. The children may be feeding off how the parents are maybe dysfunctional – that is four separate scenarios. How do you bring it all together?

Rolland: I try to help a family first to understand how it works as a family, so, how do you normally communicate? What are the limits of communication? Often with a physical problem, as in this case, in an adult, it pushes families or parents to think about how they communicate with their children that might be different to than before somebody was in pain, or somebody had a physical problem. It forces, sometimes, more openness, sometimes kids have questions – is this going to get worse, could you die from this? Did I cause it? There are a lot of initial questions.

So I'm interested how first of all – how the family communicates. How do they divide up who does what, because sometimes families have to get more creative if I'm in pain today, then I cannot do what I would normally do? There has to be somebody else who can do that. So in a traditional family with a husband and wife, how they have divided their roles, may have to be reconsidered.

Evans: But a family isn't just about roles is it? Who does what; let's say we've got a teenage boy going through all that teenage stuff. Teenagers and children can – press a button – we've got an expression – to wind you up. That's not a role but that is what teenagers do.

Rolland: Right – so one of the things I help families think about is where is everybody in their development. Because if it's a 15 year old and a 12 year old this is different than a five year old and a three year old. One of the things that gets more complicated when it's a physical problem in a family is that sometimes anger is an expression of fear. 'Could this happen to me or could I lose you?'

So sometimes in my experience when anger is being expressed in a family, sometimes it's also because they're suffering or they're anxious about what will happen. So families need sometimes some assistance to reinterpret feelings and with adolescents it's very difficult. I work with, for instance, adolescents who have diabetes, well, if they are irritable and oppositional and have behaviour problems, this could be because their blood sugar is too low, this could be because they have a chronic illness and realise they are going to grow up into adulthood and are going to have this disease for the rest of their life and this makes them more angry.

Or this could be just average adolescent or – what did you call it? Wind-you-up behaviour [laughs]. So I mean sometimes this gets confusing and families have to learn what is coming from the illness, what is coming from the pain, what is really an expression of something else because sometimes it can easily become that, issues of the family's get expressed through somebody's symptoms, because symptoms get worse if there's a lot of strain. People learn that if there's a lot of stress, usually the pain gets worse.

Pain is also invisible, so how one communicates about pain is complicated. If I say I am in pain, you might not… how are you going to question whether I am in pain? Sometimes physical symptoms start to have a currency or if parents are fighting, if a child has asthma and gets difficulty in breathing, the parents will stop fighting and focus on the child the child learns I can make the family calm if I get my symptoms.

Evans: That's right but the child can also – and they are very good at this – work out I can control my parents if I get the symptoms.

Rolland: Yes, that's possible. Often the child is afraid that if the parents keep fighting they may not stay together, something terrible will happen, so it's not fair to say it's always manipulation. Sometimes children, truly their symptoms get worse if they're watching conflict elsewhere in the family. But also they can start to use that to calm the family down.

Evans: Family psychiatrist and Co-Director of the Chicago Centre of Health, Dr John Rolland.

Now, here's an example focused on the child in the family who is ill. However, a child that is not ill but has to deal with the situation of someone else in the family who is ill, has a different set of issues to deal with. Family therapist Jan Parker:

Parker: This is a family that I worked with a few months ago and the young boy, who was 12 at the time, had been referred because of his violent aggressive and challenging behaviour at home and at school. I mean it was quite extreme what this kid was getting up to and doing

and the levels of distress that he was displaying and also that he was causing others. Adults were starting to be frightened by the force of his temper and also the destructive power of that within the family and within school and he was at risk of being chucked out of school yet again.

He came with very individualised referral information: you know, this child is this and this child is that, he has done this and he has done that. When we brought the family together to talk about how we might work well and most usefully with them, it turned out that his youngest sister was in remission from a long term – a good amount of years of cancer treatment – things were going well for her but the family focus had gone, necessarily, onto this young girl, around the time and through the years of her treatment and recovery. And this young boy's very favourite grandparent, his grandmother, had died.

And by getting together and talking through and doing like a kind of family map of what had happened and when and who's important to whom and what relationships were in the family, who was close to whom and what relationships had fallen further away. The mother realised that she found it quite difficult to even begin to describe what had happened with her relationship with her son because she felt like she had lost him. She also talked of fearing that she will lose her daughter and also the experience of feeling so helpless and at a loss of what to do and her daughter was experiencing pain and not being able to help and how stripping away of her sense of worth and value and competency as a parent that had been. And about the experience of her handing over her young child to a team of professionals to care for – how that had rocked her relationships with her own self-image – with her relationship with her husband. How her focus and vision had become a bit tunnel-visioned on her daughter.

Just being able to all gather together and the conversation became about not 'how to fix my naughty boy son' but about the impact of pain and fear on the family. And they came back once and said, of course, they had a long way to go but they had realised that how pain had kind of shrunk their possibilities and sense of what they could do in the world together and they had felt buffeted and depleted by it. And just having a pause and pulling back and looking at the wider picture had enabled them to begin to see where they wanted to reconnect and make steps to do that.

It was such a joy to see them come back, they had been to Pizza Hut and had started to work at connecting again and just doing things like playing scrabble as a family. And this lad was still, I don't think he was ever going to be an angel, but he felt like he had a place again, he felt like he had a belonging again. And his sister's experience of pain and his family's

experience of their pain and their relationship had kind of shoved him to the periphery and they were making steps to come back together.

Evans: Jan Parker for the Association of Family Therapy, Dr Elaine McWilliams again.

McWilliams: I was based in a hospice and we had someone who was going to be admitted (and there was a lot of concern. I think this goes wider than the family – this now goes to the professional family, if you like) who also had a diagnosis of manic depression. And because I'm a mental health professional they were very keen for me to support this. And they were actually very nervous and there was a lot of concerns, so I said okay I would put aside two days in my diary for this person coming in, so I can meet the patient herself and meet the family. I can then talk to the staff and I can be there to support this.

So this is what I did, I met the patient and, you know, her mental health diagnosis had nothing to do with where she was or her pain – and I mean total pain – it had nothing to do with that really. Her concern was about leaving her beloved daughters – adult daughters, who had children of their own. But nevertheless that was where her real pain was. It wasn't really about her recurrence or the fact that she could not long now be cured. [Laughs] It was about leaving her babies, her girls and how would they be.

This was a very matriarchal family – mum was the centre – the hub. And there was a lot of love in this family so I spoke to the daughters and heard their stories and then I got them all together and got them to share their stories and then I went to speak to the staff and reassure them and listen to their concerns and we had a really successful intervention – we managed her pain which had been unmanageable in the community. And the family had been making lot of demands on professionals, because they were anxious, they were scared, they were frightened, they didn't have a kind of road map, if you like, of what was happening and what was going to happen.

She was discharged home and I supported the daughters, she actually didn't really need much more input from me, supported the daughters on what was to come and where they were going and their concerns and anxieties. I was just amazed by the resilience of the family once they had had a little support and understanding – a huge amount of resilience, they coped so well, they really did.

Rolland: Sometimes what happens is that when one person is in pain, then the other family members feel that we shouldn't do things that he can't do because then we will make him feel bad. Actually, paradoxically, that is not good for the family, because if everybody gives up all these things because they don't want dad to feel bad because he can't walk in the

woods anymore, then people get angry and people feel that the pain is controlling everybody's life.

In marital relationships, this is very important, if the well spouse gives up everything they can become very resentful – not only are they providing care-giving but they can't do what they want. It's much better I think, for the couple to negotiate that maybe once a week that the partner who doesn't have the pain, does something with a friend that they would've done with their husband so that they feel that the disease isn't controlling them. This actually is healthy for the relationship and is part of what I have to help couples with so that they have to define, allowing more separateness at times to preserve the marriage.

McWilliams: One of the areas I feel is maybe neglected as well is about how pain interferes with the intimate relationships – sexual relationships, but real intimacy as well. I think these things are very difficult to talk about as well and its one of the things I try to open up a conversation, with the patients if I can.

Evans: So how do you do that?

McWilliams: I ask: 'how is your relationship with your husband? How is your relationship with your wife in terms of your intimate relationship?' And if they say, 'do you mean sex?' And I say 'well, everything including that.'

I remember working with a couple who were in their eighties – I have permission from all of my patients to use some of their information in anonymous form for teaching and other purposes – and I wrote a paper that was published on this that was looking at these issues of intimacy and attachment and the sexual side of intimacy. And for this couple, they had hit a crisis, she had a terminal diagnosis but she was reasonably stable at this time and was quite well.

Her pain had been managed but there was other pain and the medical nursing team came to me and said could you kind of see this patient? I wanted to see them as a couple and it emerged that the sexual side of their relationship was incredibly important to them and always had been and this had started to breakdown. And she actually felt that he didn't want her anymore and that she was no longer attractive because of the cancer. He actually felt that he couldn't approach her in terms of full intimacy because he was frightened of hurting her.

So they had these two stories if you like but they hadn't shared them. So they shared them and we talked about that and that changed things and they were much happier. I later saw them a couple of times afterwards and they were doing really well, she actually didn't need

as much pain medication after that. She eventually did die and I saw the husband a few times afterward and he was doing okay, deeply grieving but his memories of the last few months of their relationship together had been good and it could have been very different.

Evans: Dr Elaine McWilliams. So how widely available are family therapy services? Jan Parker of the Association for Family Therapy:

Jan Parker: It's very much still, unfortunately, a post code lottery. It's usually there somewhere if you know how to ask for it. There's information available on the AFT website on www.aft.org.uk about how to find a family therapist, what routes to take, who to ask if you feel that it would be helpful to you. There is also information about what family therapy is and professionals find this useful as well as family members.

Evans: So I'm getting the impression that a family therapist only comes in when things are identified as having gone wrong – wouldn't it be better for somebody in the system to start with a family therapist, listen your child, your husband is in chronic pain, this isn't going to go away, let's start here because this is what you're going to face.

McWilliams: Yes, I think that is a hugely important point. And again in some areas and in some services, that is beginning to happen because it makes common sense that the family resources are brought together to support the person in pain and those who are going to support them. And in some areas it just is not happening, so it's a question of political will and also a shift in service mindset. We still in this country have a very individualised, medicalised model that places any situation any suffering any circumstances within the individual. Things are changing, thankfully, there is a real sea-change in attitude, but it is yet to roll into a kind of revolution of practise and service delivery that would actually make a real difference, you know, it's patchy still.

Evans: Jan Parker. And here's that web address for the Association of Family Therapy again – it's aft.org.uk. And I would just like to remind you that you can put a question to our panel of experts or make a comment about our programmes via our blog, message board, email, Facebook or Twitter. And all the details including where to write to are at our website and that's painconcern.org.uk.

I'll leave you with Family therapist Jan Parker:

Parker: Families will enter the room looking like it's a little bit like it's a group trip to the dentist because they have a sense that they have come to have their problems investigated. That they've done something wrong and our job as family therapist is to *root that out* and *fix them.* Families feel very relieved and heartened by the experience of the process which is

very different. It's about… families having opportunity to recognise their strengths and their resiliences to draw on those and build on those. And every day I feel very humbled about what people can do together.

Contributors

* Dr John Rolland, Clinical Professor of Psychiatry, University of Chicago and Co-Director, Chicago Centre for Family Health

* Jan Parker, Association for Family Therapy

* Dr Elaine McWilliams, Consultant Clinical Psychologist

Contact

Pain Concern, Unit 1-3, 62-66 Newcraighall Road,
Edinburgh, EH15 3HS
Telephone: 0131 669 5951
Email: info@painconcern.org.uk

Helpline: 0300 123 0789
Open from 10am–4pm on weekdays.
Email: helpline@painconcern.org.uk

To make a suggestion for a topic to be covered in ***Airing Pain***, email: suggestions@painconcern.org.uk

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