

Airing Pain Programme 60: Pain in the family – young adults II

How pain affects the relationship between adults and young people and tips from a family therapist.

In the second of our two programmes focusing on young carers for people in pain, we hear about the effect of pain on relationships between parents and children.

Family therapist Liz Forbat explains how pain can disrupt transitions from childhood to independent adulthood, especially during those difficult teenage years. She discusses with presenter Paul Evan's his 'martyrdom' approach to managing chronic pain – he recalls keeping his children at a distance from it – and the dangers of building barriers between family members in a bid to protect them from the effects of the pain.

We hear the young person's perspective from Kim Radtke, who grew up with a father often made irritable and emotionally unavailable by his ankylosing spondylitis. The situation was exacerbated, Kim says, because she and her brother did not fully understand the condition and were therefore unable to empathise and communicate with their father about it. Only as an adult has she been able to make the step – so important, according to Liz Forbat – of separating the pain from the person.

Paul Evans: You're listening to **Airing Pain**, a programme brought to you by Pain Concern, a UK-based charity working to help support and inform people living with pain and healthcare professionals. This edition has been funded by the City of Edinburgh Council and NHS Lothian through their self-directed support innovation fund.

Now, this is the second programme looking at issues faced by young adults when a family member has chronic pain. Previously we heard Erin McGuigan's story of how her condition impacted on the lives of her siblings. We also heard how members of the Scottish Youth Parliament are pushing for change in the support received by young carers through their Care, Fair, Share campaign. In this edition, I'll be looking at the importance of good communication when that generation gap seems too wide to bridge.

Liz Forbat: Teenagerhood is the most difficult developmental stage, it's the most difficult stage of life. They've a great capacity, I think, to feel and to begin to understand their place in the world.

Kim Radtke: We kind of had an idea that, you know, that he had a lot of pain, and things like that,

but the actual scale of it and how much of an impact... was really difficult to understand.

Forbat: They're in the position of not being children, not being adults, but experiencing these big issues, with a parent or a sibling, that's impacted by pain. Whether you conceive that as difficulties in having attention taken away from them, or just about this extra lump of difficult life stuff to deal with, on top of being a teenager; I think it's a really tricky position for them and for the parents and other siblings.

Evans: Liz Forbat is a research psychologist and family psychotherapist. She researches into physical health problems at the University of Stirling and works as a therapist with families, individuals and couples whose lives are impacted by those physical health problems.

Forbat: Ordinarily I think, health services are organised around individuals with the disease. And we see that in the National Health Service and in private care, where it's the individual that receives the service. But actually we can only really understand the impact of the ill health if we're looking at the family more widely.

So, whenever a diagnosis comes into a family, you see ripple effects on everybody else within that. So if somebody receives a diagnosis of cancer, for example, or has persistent pain, chronic pain, what you'll see is that that impacts not just on the individual, but other family members. So that might mean that it restricts activities, not just for the individual but for the wider family. Or it may be in terms of how they relate to one another and what becomes important within that relationship.

We've done work around children with life-limiting conditions where pain's very often a part of that. What you do see, and what's very clearly evidenced in the research literature, is that siblings are put in a position where they're growing up faster. So they might be old beyond their years. In families where that becomes difficult, and it can for all sorts of reasons, you might see siblings adopting all sorts of different ways of communicating how that impacts on them. So you might see, for example, school refusal coming into play. And that comes about for a number of different reasons. So, for example, if you've got a child, a young person with some sort of pain condition, persistent chronic pain, and other siblings in the family taking on a role of looking after them...

Now that may not be physically looking after them. It may not be what as adults we identify as being a 'carer' role as such. But where a young person starts to feel like they are responsible for the emotional or physical well-being of someone else and taking on that role – and what you might end up seeing, what we've seen in research and somewhat in clinical practice – is that siblings may start to say they don't want to go to school, and to find ways of staying at home. And that's not necessarily because school is dreadful and awful, but it's because they really like they're tied to the home and tied to the sibling, so that they can offer that ongoing care and support.

We've done work with siblings where the well sibling has gone into school and basically can't concentrate all day, and spends the entire time thinking about what's going on at home – are they [the ill sibling] getting the nurturing and care and support that they need?

And that's regardless of whether or not there are adults around that can manage that, you know, but it's the responsibility that's internalised and then acted upon by these siblings. So it has a profound effect on all sorts of things. It might come out as school refusal or school avoidance or whatever, but actually, what we know from the evidence from clinical and from research evidence is that that comes from a way of relating to and wanting to relate to the person with the pain condition.

Evans: Kim Radtke, originally from the United States, now lives in Edinburgh. Her father has ankylosing spondylitis and rheumatoid arthritis.

Radtke: He's had it for at least 20 years, which means that I was about six or seven when he was initially diagnosed. And for a long time, it really didn't make any sense to me. It was very difficult to understand why he was so angry all the time, because he always was, he was very angry. And again, when he worked nights, we wouldn't go to a childcare centre or something during the day, we'd just stay at home in the summer time when school was out and kind of creep around the house quietly. It was kind of this game of 'don't wake the bear', where if you woke him up he would be just so angry – disproportionately angry – and as children that was just really difficult because you didn't understand what you had done wrong necessarily or why he was so mad. And it was, you know, it was very hurtful.

It was very difficult for my mother. A lot of times, for family functions or things like that, we would try and plan in advance things to do, and then he wouldn't be able to follow through on a commitment he had made, or just being able to go to things. I really didn't understand as a child why my parents didn't separate, because I always saw my mum being really sad or upset with the way that things played out and I just couldn't understand why she would put up with that and why she, or how she, could still love him, despite him being, you know, really difficult and angry and letting her down like that.

And it took me until I was an adult to really understand that the frustration involved in that whole process of letting people down – it's not just the anger that you [feel] or the frustration that's from the other people around you, but it's also, you're frustrated [laugh] because there are things that, you know, you want to be doing these things, you want to be able to make commitments, and it's not just the things that are important to other people that you end up missing out on, it's things that are important to you as well.

Evans: And anger is an instant thing, it's a now thing. But resentment festers.

Radtke: Yeah. And I think that's something that's very marked in my family as well, because my brother hasn't been able to form the kind of relationship with my father that I've managed to get. And part of that is because he left the household – he's a few years older than me – so he left the household a few years before I did. And it wasn't until I was kind of in my mid-teens – and about the time that my brother left the house – that they finally got an effective treatment regime for some of his pain. Once he started that, there was for him something of a marked difference in his ability to actually just participate in our lives a bit more.

But, because I had those couple of extra years in the house, overall, now even, my relationship with our father is much better, because my brother never had that chance to live with him when he wasn't in that kind of reactionary mode, where, you know – 'I'm in pain, this is...' – you know, that reaction, where my brother still has a lot more of that kind of lingering resentment of, 'you're always angry for no reason'.

Evans: But you're talking as if the drugs have cured the problem

Radtke: They haven't, they haven't cured the problem. It was the first thing that actually made an impact on his pain and that was a decade after being diagnosed. He finally got something that for a couple of years made a difference. But having that couple of years where he was in less pain and able to do better managing his pain did make a big difference in our ability to form a relationship and I'm quite sad that my brother didn't have that chance or that experience as well.

Evans: Kim Radtke. Now, at the start of this programme, Liz Forbat described the teenage years as the most difficult stage of life. Parents might argue that it can be as difficult to live with a teenager as it is to be one. There may also be younger children in the family. So, how would a family therapist deal with the different and maybe competing issues of each age group?

Forbat: One of the lenses which family therapists use is to think about life cycle issues. And by life cycle issues, I mean that you'd approach the family and each member within the family and try and understand what was going on for them in terms of their usual developmental cycles. So for example, you'd expect age five to be heading into school, age 16 to 18 heading out of school and then somewhere around early adulthood, maybe entering university or the workplace and that sort of stuff.

So what you'd be looking at is, does this existence of persistent pain within the family, does that impact on any of these life cycle transitions? So in early adulthood, you'd be looking at, does the existence of this pain condition and the difficulties around that, is that pulling that young adult back

into the family and is it disrupting regular life cycle patterns that you'd expect to see?

John Rolland, who works in the States in Chicago, talks about centrifugal and centripetal forces. And I don't know if you remember any of that language from chemistry at school

Evans: The centrifuge pushes everything to the outside.

Forbat: Yeah, exactly. So centrifuge is a kind of, splat everything out with, and centripetal kind of pulls things towards the middle. So if you imagine a cylinder, and family members within the cylinder, and forces either push people away to the outside of the cylinder or into the centre of it – that becomes the centripetal/centrifugal forces. So this model helps us think about what happens when illness and pain comes into the family: does it push people away or does it pull them in? And often what we see in young adults is that they get pulled back in, and they get pulled back in to the centre of the family and around the individual with the physical health problem. And that that might be seen as unhelpfully disrupting some of the regular patterns that you'd see, with somebody leaving home and going off to university, or maybe setting up their own family and so on.

So that might be one disruption. I guess another disruption might be at other points in time with these forces, about a centripetal force, where people get pushed away. And that might be with the ongoing presence of persistent pain, that it becomes a real difficulty for other people to continue to witness it and to often feel very powerless to do anything about it and to feel like they can do anything to intervene and lighten this for the individual. So you might see that also at those critical life junctures that people feel like they're being pushed away. So you might see somebody making a decision to not live and work and study or get a job in the local area but suddenly feeling like they want to go as far as they can.

Evans: Family therapists talk about centrifugal and centripetal effects in families, where the centrifugal force pushes things out to the outside; the centripetal force drags things into the centre. It sounds to me as if you and your brother are one and the other of those.

Radtke: I would definitely agree with that. And it plays out in our larger family as well, where my mother's family, so her brothers and sisters, her parents, they really had a much better grasp, I think because my mother spoke with them, about what was going on and they had a much better communication thing. So, they were much more accepting of – 'yeah, he can't be here today' – and were gonna be forgiving of that. Where his family, probably partly because he didn't communicate with them in the same way as I'm saying my mother did, they didn't get it and they were quite hard on him.

Evans: You talked about wondering why your mother didn't leave your father. That may the level of

understanding of a child looking at their parents. In retrospect, can you see why your mother didn't leave your father?

Radtke: Yeah, I can. They have a very committed relationship because – he was quite young, he was in his mid-twenties when he was diagnosed with rheumatoid arthritis – so it was, you know, accepting this as a part of him. But also, throughout the process of coming to understand his pain and being able to separate that from who he was; as children, that was just something that we couldn't understand. And being able to see who my father was when he was being himself and being pain-free, and being able to see the pain as a separate part of him, different from his personality, different from his normal thought process, that, as I've become an adult, it's something I've been much more able to appreciate. And again, as a child, I just didn't have that concept: he was who he was. Obviously her understanding of that was much better.

Evans: They obviously talked to each other. They communicated well.

Radtke: They did communicate. I mean you have to, you have to be able to work together, or the relationship wouldn't have worked out.

Evans: It sounds to me that pain was in the house. And maybe your parents were dealing with it, but they didn't realise that their children, you and your brother, weren't dealing with it.

Radtke: Yeah. I would say that that's probably true.

Forbat: Communicating with each other about the pain, the impact on everybody within the family system is an important thing to do. That's not to say that the same kind of communication is the right thing in every family – I know my family communicates in a different way than my husband's family and that that's right for my family and his family's version is right for them – so I don't think there's a correct way of managing that. And the decisions around that would have to be based on each individual family's history of how they talk about illness, how they talk about supporting each other – what their historical approach to caring for each other looks like. So I think making sure that family members feel like they can talk about it and get it out in the open, rather than being something that only one individual has to cope and manage and deal with on their own. To make it something that the family own as a whole and can manage as a whole is important, but I don't think there's one right way of doing that.

Evans: You see, with my experience – I have chronic pain and have had so for 25 years... and my children have grown up through it – looking back at how I dealt with it, I kept it very personal to myself, but it did break out in anger. They had to push me over that tipping point and I would explode and create an atmosphere and then it would be gone, at least I thought. Is that a correct

way of going on with it?

Forbat: Well like I say, I don't think there's a correct way. It sounds like if you're labelling it as anger, then it didn't feel right in retrospect. Looking back, it sounds as though you think there might have been other ways of managing that. I guess what you're talking about is something that's very typical of families affected by ill health, persistent pain being one of those elements, which is, the person with the condition holds the stress of that for themselves and they've worked really hard on protecting their family members from knowing about it.

Evans: It's my condition, I'm going to manage it.

Forbat: Yep. And some of that's about ownership of it and some of it's about protecting other people and thinking, particularly with children – and spouses I think too – that the individual with the condition wants to just manage that on themselves. And there's a label for that.

Evans: Martyrdom?

Forbat: [Laughs] Well martyrdom works! The psychological label's a bit different. We refer to that as 'psychological buffering'. We all know what buffers are and it's a way of protecting and creating some space between... And we see that a lot in therapeutic practice, where the individual with the condition tries to protect other people from it. But what that doesn't recognise is, other people within the family are impacted and that the buffering actually just creates a barrier rather than a protective barrier. And so the anger response is from when things get higher than the buffer is. So if the buffer is 6ft or 60ft tall and suddenly the burden and the pressure of the illness is just a millimetre above that, that's when that pores over into anger.

Radtke: Right now, one of my biggest concerns about my father is with the prolonged use of steroids. He has put on quite a bit of weight, he's had difficulty managing his weight, and so I do worry that he will develop diabetes or have a heart attack or something like that. And so I do try and discuss that with my brother and he's very much less willing to communicate with my father about anything regarding his health. They're not part of the way he interacts with our parents.

Evans: But conversations aren't just one way. I can remember with my own mother, who had very, very bad pain at the end of her life, and sitting down with my mother, knowing full well that she was dying and in a lot of pain – but my father having been forbidden to speak to me and my brother about what was wrong – and sitting down with my mother as we are now, eyeball to eyeball: 'Mum, what is wrong? Can I help?' And she saying, 'No, nothing wrong.' Many parents do find it difficult to talk to their sons; daughters are easier.

Radtke: Yeah. [Laughs] And again that kind of gets into our gender stereotypes of how we actually

interact, but that may be a big part of it. My parents don't broach the subject with him either, because they know that I have a lot more interest in finding out about it and keeping up to date and being able to be there for them, they do now talk to me a bit more about it.

Evans: So they accept you being there for them.

Radtke: Yes. They do now. You know, if my mum's having a really hard day, being able to put up with him being cranky or something like that, she'll call and just have a bit of a whinge about it. Because you do need to, as someone who is the carer, have that space to be able to talk about it. And I've really spent some time pushing my mum to talk about it with someone. Obviously you need to have support for yourself as a carer.

Evans: It can be very cruel – and I use that word advisedly – it can be very cruel on a young adult carer, on a son or a daughter, when they're frozen out of their parent's pain condition – for the best possible reasons – to protect the children. But it can be very cruel for the child, in my opinion

Radtke: I would agree with that and I think, particularly my father and my brother, would do some of those typical father/son bonding experiences; they were both sportsmen so they would go fishing quite a bit. And so I think it was really difficult for my brother as a young adult when my father and my brother would plan some sort of activity, like plan to go fishing or something like that, and my father would be having a bad day and he wouldn't be able to get into a boat and sit there for hours... Because they didn't have that kind of communication, you know, my brother, he would feel rejected – and I think he still carries a lot of that with him and if they had talked about it more, I know that their relationship now would be better.

Evans: I used the term 'martyrdom', 'martyr', and we both had a laugh about it – but it is a serious comment isn't it? If I were coming to you with this issue, how would you start with me?

Forbat: The start would be to understand the history of pain. And some of the ways in which I might start a conversation around that would be to ask you – when did pain first arrive in your life? when is pain at its strongest? when does pain find itself to be most powerful in your life and relationships? And if you were coming with your family, that would be something that we could open up to other people. So, who is it in the family that notices when pain is most difficult for you?

Evans: As the martyr in the family with pain, I would say, it's me. I would be oblivious to what is happening around me with my three children, with my wife, with my parents indeed.

Forbat: Oblivious to the impact on them, do you mean, or...

Evans: Yes. It's my pain. I'm suffering for this, not them.

Forbat: Yeah, and that's a really difficult position, I think, if one person in the family feels like it's just their burden. Depending on what the session felt like, it may be that I would invite the person that was in the martyr position to take a listening role. What I might do in that situation is think about a conversation with the other people in the family that were in the room and to ask them about what was going on for them. And to invite the individual with the pain to sit, to listen and to then maybe reflect with me about what they've heard. So, what that does is to open up a different way of understanding what's going on.

Now I know that can be a very difficult and challenging position. That wouldn't be what I'd do in a first session. I think there would be a need to build up a relationship with the individual, because I think that's a very challenging position to be in – just sitting and hearing what pain looks like to other people. But that might well be a way of challenging this idea that it's just one person's burden, if you like. I think, from a first session perspective, what I'd probably do is to look at the strengths within the family and how it is that as a team, you could gang up on pain.

Evans: Ganging up on pain as opposed to ganging up on the person?

Forbat: Yeah. So we leave you out of this. And we try and separate pain from you. You're not pain; you have pain, but you are not pain. So tell me about the time before pain came into your life: what was life like for you at that point? Was it in your life when you met your wife? Was it in your life when you had your children? And to tell me a bit about who you were before pain arrived in your life and to map out some of that – to understand you as an individual as separate and distinct from pain. And whilst understanding that [whilst] actually it feels very integrated at the moment... and by doing that, by separating person from pain and seeing the problem as the problem, not the person as the problem, you can build up a team approach, thinking about the strengths that other people in the family bring, that can help get rid of pain or can help keep pain in its place

Evans: Staying with a martyr theme – let's turn the tables round and the person without the pain, the young adult – whose parent has pain – he is now the martyr. How do you deal with him or her?

Forbat: So the young person is the martyr because their life has been so impacted by...

Evans: They can't go out in the evening, they can't go on their skiing holiday to Austria with the school, they can't go camping with their friends, can't go to football on a Saturday afternoon. You know, they're getting hammered by mum's pain.

Forbat: It doesn't really make much difference whether or not it's the young person with the pain, or the parent with the pain – it's starting to understand that pain can be seen as separate to, and impacting, everybody in different ways.

Evans: If, with the benefit of hindsight, we can't take your father's pain away from him, but we could deal with it as a family differently, how would you do it now?

Radtke: I think that, when there is an initial diagnosis, to sit us down and actually talk over what the condition is and what it means and then just to overview what the impact will be. Because for them to say, 'Oh, he's got arthritis – and, you know, that means that he's going to be in pain or whatever', we didn't understand that that would mean that it would affect his sleep or these knock-on effects. And it took me a long time to realise how the pain effected his personality and the way that he related to people, both within our family and outside our family... I mean it did, it affected everything. And just spending more time making sure that everyone understands what that can actually do.

Everyone's needs will be changing throughout the process, and you have regular check-ins – and I think that's one of the important things – to make sure that everyone gets a chance to say how it's impacting them. Just to have a more thorough conversation and to do it regularly instead of just when something's wrong... to check in and talk about things when they were going OK, when they were going bad and when they were going good, just to have lots of communication about it.

Forbat: Retrospect – you know, hindsight is 20/20 – but by speaking to the people that feel a little bit further on than you and learning from them about what they would want. I guess as a family therapist I'd say maybe you should all think about family therapy, maybe that would be helpful?! That's not for everybody, but I think certainly being exposed to other people with personal experience – you know, people who are experts by experience – that's a really powerful way of enabling some of that learning and to short-circuit some of that for people.

Evans: How would I find a family therapist? Or, how would my wife find a family therapist? Or my children?

Forbat: Family therapists are ordinarily registered on the UKCP, the UK Council for Psychotherapy, website. You might also find other practitioners registered on other professional bodies. So you'd be looking at somebody that's registered as a psychotherapist and that means that they've undergone appropriate training, they get supervision and continue with their professional development and so on. So you'd be looking at maybe UKCP websites to find family therapists.

Evans: That was family psychotherapist Liz Forbat. And the UKCP – that's the UK Council for Psychotherapy website – is psychotherapy.org.uk. Now, Pain Concern has also launched specific services to support young adult carers: through these programmes; its forum, where you can connect with your peers; articles in *Pain Matters* magazine and information leaflets. All details are

at our website, which is painconcern.org.uk

I have to remind you that, whilst Pain Concern believes 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 well-being. He or she is the only person who knows you and your circumstances and therefore the appropriate action to take on your behalf. Don't forget that you can still download all editions of ***Airing Pain*** from our website, once again, it's painconcern.org.uk. Or you can obtain CD copies direct from Pain Concern.

So, to end this edition of ***Airing Pain***, I asked Kim Radtke for her advice to young adult carers who find themselves in the same situation that she found herself in...

Radtke: Try and get some information for yourself. Go out and see what you can find so that you have a base knowledge of what's going on. From there you can say that, you know, 'this may not be you, this is you with pain and that is different.' We have to acknowledge the presence of pain. Once you acknowledge it, you can actually start to work on its impacts on your relationships and on what you're doing with your life and how you are relating to everyone around you.

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