Airing Pain

Programme 140: Childhood Pain: Adverse Experiences and Parental Relationships

Paul Evans: This is *Airing Pain*. The program brought to you by *Pain Concern* the UK charity providing information and support for those of us living with pain, our family and supporters and the health care professionals who care for us. I'm Paul Evans, and in this the first of two editions of *Airing Pain*, focusing on issues faced by children and young adults. Today, I'll be looking at how childhood experiences and relationships can impact on pain in the present, and in later life.

Katie Birnie: We want youth to see themselves as more than their pain, right? That's so important. People are whole people. They have other interest activities.

Jen Ford: The joy of working in a lifespan service is that you can put people where they should be rather than the age that we feel they should be working in.

Lauren Heathcote: You know what's it like when you're a parent of a child who's had cancer previously, and then they say, like, mum, I have this new headache and it's not going away. And I don't know what it means. And it's scary.

Tim Hales: The most impactful aspect of what we're doing will be to potentially provide scientific evidence that an individual who's suffered from childhood trauma has a higher likelihood of developing chronic pain.

Evans: Adverse Childhood Experiences refer to some of the most intensive and frequently occurring sources of stress that children may suffer in early life. And according to the World Health Organization have lifelong consequences for a person's health and well-being and can lead to chronic pain in later life. Such experiences include multiple types of abuse, neglect, violence between parents and caregivers, other kinds of serious household dysfunctions, such as alcohol and substance abuse, and peer, community, and collective violence. CAPE, that's the Consortium Against Pain Inequality brings together people from a wide range of backgrounds to understand the impact of adverse child experiences on chronic pain and how people respond to treatment. Professor Tim Hales, a project lead with the consortium, is a non-clinical professor of anaesthesia at the University of Dundee.

Hales: These adverse experiences are conventionally divided up into three areas, so that would be abuse, neglect and household dysfunction. So, abuse is pretty clear I think, what that means. Sexual, physical abuse. Neglect, I think also that's fairly clear. Household dysfunction might be a parent who's incarcerated or is substance dependent or an alcoholic. So they are generally assessed largely retrospectively, but sometimes prospectively in childhood, and we use questionnaires to do that type of assessment and typically there would be about 10 different items that might be listed on that questionnaire. So we're very interested in whether those questionnaires are adequate. Could we make them better? And

are there links between those types of adversity in early life and chronic pain in adulthood. And if there are, what kind of mechanisms might store that memory?

Evans: Who are you interviewing? Is it the parent? Is it the adult who has been abused as a child? Where are you getting your research from?

Hales: We're particularly interested in both ends of the spectrum, so we're interested in adults. We've actually got a population of elderly adults, and we've asked them to recall their recollections of early life adversity or childhood adversity. We also have a cohort of juvenile idiopathic arthritis patients in London. They're around 18 years old and so their experience is a little bit closer to hand. But still, that's still retrospective, we're not actually asking children to tell us about their current exposure to adversity.

Evans: But for the 18 year olds, I mean that's still very, very close to what is going on at home or anywhere else for that matter. How do you approach those difficult questions?

Hales: That's a very good question. So, in that group of individuals, we have them fill out a questionnaire with a researcher present who has a good understanding about where they could be referred if they have any issues that might arise from talking about those experiences. We have a list of resources of places where individuals who've suffered from adversity in early life and maybe have problems addressing those issues where they can go to talk to and receive help. And, of course we can also refer them to their GP or their consultant. In this case, these patients are all currently receiving care from University College London Hospital. That's one aspect of the project, but we're also looking in the other age spectrum at the elderly cohort that we're studying in Edinburgh, which is called the Lothian birth cohort of 1936. So, these individuals are in their 80s, as you can probably tell from the name of the cohort, and we're asking them to recall adversity in early life and looking at their responses to our pain questionnaire.

Evans: What are their memories of what went on and how it affected them.

Hales: Yes, it's a very interesting question because back in the 30s things were quite different from the way they are now obviously. And when we've looked at the questionnaire responses, some of the participants in the Lothian Birth Cohort study indicated that life was so different then, that it's hard to look back at it in the context of adverse childhood experiences, because in those days, you know, physical punishment was something that wasn't considered extraordinary by any means. So, that does raise an interesting question. And I think one of the things that we'll find out from the study is how many people from that generation report exposure to adverse childhood experiences? It might be that the numbers will be much lower because people don't consider some of the things that we might now consider to be an adverse experience to have been adverse in their day. So that would be very interesting to find out. There's not simply the link with chronic pain, but also those more fundamental questions about people's attitudes.
Evans: And of course they were the war years.

Hales: Yeah, we actually selected the questionnaire specifically, so it would include issues around war like displacement. It's like peeling an onion in a way you you don't know where to draw the line with questions because racism is a legitimate concern, obviously, and should probably also be an adverse childhood experience, sustained exposure to racism is obviously, very stressful. So there's a question about how the questionnaire should be designed and that's one of the things we're trying to tackle as well.

Evans: That's Professor Tim Hales project lead of the Consortium Against Pain Inequality. So what could be going on with these adverse experiences in childhood that feed through to chronic pain in adulthood? Lesley Colvin is professor of pain medicine at the University of Dundee, she's also a project lead of CAPE.

Lesley Colvin: There's increasing evidence that adverse quality experience have long term impacts on the neurobiology of the pain systems, and we know that there are changes in the stress response. There are changes at structural and functional level within the brain that potentially may predispose you to developing chronic pain in adulthood, and indeed it's not just chronic pain, there's a link with many other physical and mental health co-morbidities such as depression, cardiovascular disease.

There's also some recent work actually published in this week's British Medical Journal, which shows an increased mortality associated with childhood abuse, and that's a large scale study, I think of about 70,000 nurses and looking at experiences in early childhood and adolescence. And there's a clear increase in behaviours associated with increased health risks, so smoking low levels of physical activity are two of them and an increased mortality, particularly mortality related to injury and poisoning, respiratory disease, possibly secondary to smoking. Also, cardiovascular disease and digestive disorders. So you know, we need to take a kind that actually unless you intervene early and identify as a problem, you're not going to either understand the mechanisms to reduce the impact, and going forward, how can we prevent it.

Evans: Now I can understand some of the things you just mentioned. Smoking, obesity, lack of exercise. But chronic pain, though, how are they linked?

Colvin: So in terms of the mechanisms, there are some interesting links. So if you look at brain imaging studies, there are clear effects of adverse childhood experience in brain imaging responses in adulthood, and the bits of the system that are affected, this bit, the kind of broader bit of the system, the corticolimbic system, which is also the bit that if you do functional brain imaging and you scan for chronic pain. But so that's the same system light up and also interestingly similarly with depression. But actually, as a working clinician, you can't work in a pain service and not make that link when you see the patients that are coming through the service, you're taking a full biopsychosocial history that adverse childhood experience is so commonly there. So it's that predisposing factor. But one of the things I think it's important to understand is. So not everyone who's adverse childhood experience will go on to develop chronic pain. So maybe there's something to be gained by studying individuals who have had adverse childhood experiences who don't go on to

develop chronic pain because then you can start to understand what factors, what mechanisms mediate resilience. And can you build on those and there was an interesting paper published this week actually, which is not looking at chronic pain, but it's looking at substance use disorder and adverse childhood experience. And that's a mixture of looking at some biomarkers and also neuroimaging and what they found was that individuals with adverse childhood experience who don't go on to develop substance use disorders have higher baseline levels of endocannabinoids, particularly [unintelligible], and actually when they're asked to do a task, a stress related task. The levels remain higher, so there's something protective about that, and also when you did the neuro imaging work in that there was decreased connectivity between some areas of the brain that are involved in emotional processing. If as a clinician you are assessing a patient in front of your clinic, how many of us actually ask about adverse childhood experience and if we do ask, how do we ask about it? And that's attention because you've got a lot of information and there's a lot to do in an appointment that is of necessity time limited. And the last thing you want to do is to ask an individual do it in such a way that it causes additional trauma to them. So awareness and knowledge and support in terms of training as to how to manage that, and deliver that kind of trauma informed care is really important.

Evans: So how do you manage that?

Colvin: One of the things is you know, building the rapport, being in a safe space and doing it in a sensitive way and allowing the patient that you are interviewing to disclose or not, as they feel able to, and if they do disclose, then making sure that there is appropriate support available. There are charities like well be in Scotland that will provide support, you don't need to be referred, they can refer themselves, but also being aware that there's limitations at the moment, in terms of the services that are available, so there's a conversation to be had with policymakers going forward so that we can address that. Perhaps we should be providing education around about the time where women have contact with the maternal services, because that's a time where you know you're having a baby, you almost inevitably have contact with services, and that's also a time where education about adverse childhood experience its impact and how to get support for that actually might have significant impact. So maybe working with community groups, health visitors, NCT, range of organisations. There's not one single simple solution, but I think there are approaches that we can use that will make a difference.

Evans: Professor Lesley Colvin, Professor Tim Hales, again.

Hales: We don't know currently which particular experiences might be most detrimental. There are studies that have been published that already suggest that there's a link between early life adversity, so adverse childhood experiences and pain in later life. But currently we're not aware of which adversities in early life might be most influential. We're also very interested in the possibility that there might be a memory of those adversities that stored somehow in the body that may alter the way that people respond later in life, even though those events might be many, many years before they experience their poor health outcomes, there's a large body of literature that demonstrates associations between adverse

childhood experiences and poor health in general, particularly mental health. There's an emerging understanding that that probably also extends to chronic pain. One of our main aims is to try and establish whether we can find evidence for that. That's the first thing. But also look at the potential causal factors or mediating factors that might store a memory of that. And so our hypothesis is that it's through an epigenetic mechanism. Which is a change in DNA structure that might be caused by chronic stress in early life, that then gives rise to a change in the way our cells behave later in life that's physically different from those people who haven't been exposed to chronic stress in early life.

Evans: See none of that surprises me. What does surprise me with what you're saying is that there is or could be a change in the DNA.

Hales: So this is a process called DNA Methylation. Without going into the biochemistry of the process, it's a common process that goes on in all of us that enables us to adapt to different environmental situations. There are a number of environmental stresses that can cause DNA Methylation, smoking being one, perhaps the most famous one, and you can actually use these patterns of DNA Methylation to estimate somebody's age. And in those people who've had exposure to a lot of environmental stresses, they'll have an older Methylation age or DNA Methylation age. It's becoming a very interesting area of science. We're particularly interested to see if that area can be extended to understanding chronic pain and the impacts of what happens in early life. There is another area that I think is particularly interesting and that is how people respond to analgesic drugs. So pain killing drugs and whether that also might be influenced by exposure to adversity in early life, some of these pain killing drugs are very strong narcotic drugs like opioids and there's quite a large literature demonstrating associations, very strong associations between exposure to adverse childhood experiences and problem effects or detrimental effects of opioids, including dependence and addiction. So it may be that in some individuals treatment with opioids might not be appropriate if those links turn out to be true in individuals who also have chronic pain.

Evans: Professor Tim Hales, well, we've been dwelling on adverse childhood experiences, but in for want of a better word, a normal family, how to parents mindsets affect the child with chronic pain. Lauren Heathcote is a senior lecturer in health psychology at King's College London. She studies the psychology of pain and symptom perception, primarily in young people.

Lauren Heathcote: We tend to use the word mindset to mean a core assumption about the way things work in the world, and some of this work stems from Carol Dweck's work on growth mindsets versus fixed mindsets, about intelligence. I worked at Stanford with Alia Crum, who studied mindsets about stress. Do we think that stress is something that makes us sick and weak and is debilitating or something that makes us learn and grow and makes us stronger? Mindsets about the body do you view the body as something that's capable of managing and handling and coping with pain? And is your body responsive, able to heal? And is your body working with you or against you?

Evans: I'm sort of trying to go through my own memory of what my mindset, what my parents mindset might have been that illness was something that you fight through, no such thing as illness. Get up and go to School.

Heathcote: That's a really powerful mindset or belief about illness, something that is to be pushed through, I think that relates to the idea that illness can be managed, that mindset, that illness is something that's manageable. You have control over and I do think that, yeah, that the way that our parents respond to things like when we have an illness or we have an ache or pain and that has to shape the way that we view and the mindsets that we have about things like illness or what our body is capable of.

Evans: In that scenario, maybe that mindset was correct, or maybe it wasn't correct. Or maybe it was a little bit correct. Go to school if you're still feeling ill at lunchtime. Come home and of course you never did. So perhaps it worked.

Heathcote: Yeah, I think that's such an important point that the way we think about mindsets is that they're never correct or incorrect. What they are is lenses through which we view the complex world, and but there they have meaning and they have power because they shape our behaviour and our emotions and the work that Alia Crum has done on mindsets, about stress, I think is a great example of that because stress can be both debilitating. It can make us sick and weak, and there's great research showing that over the long term, it predicts morbidity and mortality, and there's great science showing that stress helps us learn and grow and meet our goals and makes us stronger. And so our mindsets, they help us make sense of the complexity of the world, rather than necessarily being true or false.

Evans: Having said that, how do we as parents alter our own mindsets?

Heathcote: Yeah, I think what you just said is important as an important starting point is to recognise that the mindset that you have as a parent might naturally flow onto the child. So there's an active component there. You know, how do I change my mindset so that's imparted better to my child and the first step is really just recognizing that you have that mindset and that the mindset is coming out through your behaviours and your emotional responses and things like that.

Evans: I think what many people with chronic pain would say is they don't understand me. My mother doesn't understand me and I guess it's very important for the child to know how to react to that to mum doesn't understand me. Dad doesn't understand what I'm going through.
Heathcote: Yeah. I mean, I think that the validation piece is incredibly important. There's no point talking about changing mindset if you feel invalidated in some way, and that in and of itself can be an invalidating experience. You know, just change your mindset. The tricky thing about pain is that it can feel quite lonely, and it shapes the way you view your body in relation to other people's bodies. So, you know, I think my body is something that's letting me down. It's not working the way it's supposed to. Doesn't work like other people's bodies

work, and that can be quite an alienating experience. So I agree that being understood and being heard is a really important starting point as well.

Evans: When you work with children and parents, how do you approach it?

Heathcote: How I approach it from a research perspective, we always try to start with the patient voice, so I've I have a a whole research line in the experience of pain in childhood, cancer survivors and young adult cancer survivors, and there it was really important that we started with qualitative work to really understand what the pain experiences like for these children and for their parents. You know what's it like when you're a parent of a child who's had cancer previously, and then they say, like Mum, I have this new headache and it's not going away. And I don't know what it means, and it's scary, and what are the words they use to describe that experience? So yeah, from a research perspective, starting with the patient experience is really important, and then building our research questions from there.

Evans: So, what were the questions to the parents then?

Heathcote: Well, firstly, we start with the validation and that's important piece of when we do qualitative research. You know these are hard questions. So, I think acknowledging upfront that it must be really scary when your child says I have this pain and it's not going away and I don't know what to make of it, and then really asking them, you know, what does that bring up for you? What are the emotions that you have? What are the first things that come to your mind when your child says I have a headache? Normally what we hear parents say is, was terrifying because my child had this illness before, and now I'm really worried about them having that again. And I want to you know, be protective and be helpful, but they also don't want to over worry about every single ache and pain that their child has. So, we asked them things like how do you manage, worry about pain and your response and manage that sort of anxious response that you have and they tell us all these wonderful things about strategies they have.

Evans: How do you feel when you know that work you have done is actually helping people?

Heathcote: That's the best bit and I see it indirectly through clinicians who say things like, I'm speaking to my patients differently now about their pain or about their symptoms and that's just the most rewarding part of it all. Yeah, it's the best bit.

Evans: Lauren Heathcote of Kings College, London, well depending on your viewpoint, children and adults can seem like two very different species, but how far apart are they really? Jen Ford is a physiotherapist in the Bristol Paediatric Pain Clinic, and she's therapy lead at the Bath Centre for Pain Services, which is a national service for people of all ages.

Jen Ford: Sometimes people wonder, you know, if I work with adults, how can I possibly work with children or vice versa? My own experience is that, you know, children aren't small adults, and we should be working with them differently. But I certainly feel like the fact that

we work with all ages has really opened up how creative we are in sessions. I can give an example of a gentleman I worked with who was an ex-military person who he sort of described a turning point in his treatment was when we got out the colouring pens and asked him to draw a sort of physicalisation of his thoughts and emotions, a metaphor passengers on my bus and before I worked with two, and I probably wouldn't have reached for the pens as frequently as I do, or thought about being a bit more creative in how I work with people, there's a lot to be learnt from working with different age groups. One of the most interesting things is working with young adults, sort of our 18 to 30 patients with quite a broad age, because often we'll see 18, 19 year olds who are still living at home and are better treated as adolescents. Maybe that's where they are developmentally, whereas you know you might see a, a 16 year old who's living independently and you know, thinking about how to manage their future. So it's quite a broad thing and I think the joy of working in a life span service is that you can put people where they should be rather than the age that we feel they should be working in.

Evans: You told that story about picking up the crayons with the elderly gentleman that you learned from working with children. So is there something you've learned from working with elderly people, or it's just called us adults, that you can transfer?

Ford: Absolutely, and so much and I think they talk about their life experiences and how they've kind of managed with different conditions, and I think that can be so helpful and so useful for our younger patients as well. You know, we can learn from any age group for me just being a lot more open in my approach and finding out what interests the patient rather than making assumptions about what they're going to want to do, you can have any age group. Maybe there's an older adult who wants to connect better with their grandchildren and actually ohh I can talk to you about what I do with kids that age and you know it can open up some really interesting conversations and then we end up doing some very different activities, perhaps to what they or I expected.

Evans: That's Jen Ford therapy lead at the bath Centre for Pain Services, so maybe children and adults aren't as alien to each other as I at least thought. Doctor Katie Birnie is a clinical psychologist and assistant professor at the University of Calgary in Canada. In 2022, she was speaking to delegates at the British Pain Society annual scientific meeting about patients, children in her case, and family partnerships.

Birnie: What it means when I say patient partnership too is that we're working with youth, whether it's children, young adults who have their own experience with pain, their family members as equal members of our team. So they're working with us to help identify what questions do we need to be asking and answering about pain during childhood. How do we need to go about answering those questions and how do we need to share about what we learn? We looked at all of the studies, all of the reviews of all the science, for any intervention for chronic pain in kids and said, what do we know? How good is this evidence and where are there gaps? And one of the things that we identified is, at least in the context of pain in childhood, the most amount of evidence. If we look at drugs, medications, psychological interventions, physical interventions, other nutritional diet or other

interventions. The best quality evidence, and the most evidence we have are actually for psychological treatment, and that's a piece that not everyone can access. That's a whole shift, right? Often people think primarily about seeking medications and a multimodal approach is certainly really important. But psychological interventions are a key piece to supporting youth to function well, to live well and hopefully have pain that stops.

Evans: That may be a battle from the very start for the parents, because drugs make you better. Why should I go and see a mind doctor, a psychologist and not a Doctor who will give me drugs?

Birnie: It's a great question and I think when I talk back to that project where we had youth and parents and healthcare professionals tell us their priorities for chronic pain, the number one most common response we got from that was that youth had been invalidated about their pain experience from healthcare professionals, family members, teachers, coaches, peers, siblings, you name it. It's really common to have your chronic pain experience invalidated and in part, that's because pain is invisible, right? So it makes sense that people are hesitant to talk to a psychologist in the context of chronic pain, because they've often been told that phrase. It's all in your head, as if to say it's not real, and the reality is, and I always start this as a psychologist, your pain is very real and the neurophysiology of how the body works backs that up, right, you know. But it backs up that. Your thoughts, your feelings, your emotions, your expectations have a huge impact on your pain experience, and those are things that a drug can't target. And so we need to also be looking at how do we add in, how do we address, how do we target all of those other aspects of pain experience that are really critical to getting back to functioning and moving forward with chronic pain.

Evans: We're talking about young people, adolescent children, a very important part of child life is the family, the parents. Everybody has to be in on this. How do you help them help their children?

Birnie: We are talking about partnering with parents and youth in research and healthcare, how we design our health programs and parents are key to that. So we also spend time in my work talking to them about what do you think is needed, what is missing in terms of you know how our health system is designed or how our pain care is designed. Or how our interventions to support families, you know, what are your thoughts about how we can improve that? And one of the key things that's also come from that is how do we address parents who have chronic pain and what supports do they need and do they have in order to then be able to best support their kids with chronic pain or ideally even prevent chronic pain in kids before it starts?

Evans: A parent with chronic pain might have had chronic pain right through their child's life. Psychologically, they could be affected by I didn't have enough involvement in that child's life, and what do I tell my child about my pain? How do I put it over there I have had invisible pain that is affecting our lives.

Birnie: Yeah, I think it makes a difference how you talk about it in a family for sure, and I think what we know from some great research is that kids learn by watching, right. They may not be saying to their parents. I'm doing everything you're doing, but they certainly pay attention to the behaviours they observe. We call that social modelling. You know how parents are managing their own pain if they have it makes a huge difference for what kids learn about pain and how to cope with pain. So often in those situations, encouraging parents to be using good coping strategies for pain management as well, and we've actually run some groups where we've provided psychological interventions for adults who are also parents with chronic pain at the same time that we're offering psychological interventions to their kids who might be dealing with chronic pain, and seeing some really interesting feedback from families about what it's like to learn about good pain management skills at the same time and how that shifted some of the conversation within the family to focus more on, you know, kids being able to say, hey, mom, I see your in pain. I learned that I need to take some deep breaths or I need to manage it this way. Let's do that together where you this is what you need to do, and that's going to help you through this moment. So I think when we can shift some of the conversations that happen about pain and families, and the behaviours that are associated with that.

Evans: But adults in pain, parents with pain, don't get to see you should they?

Birnie: Great question. I mean, you're right, not everyone can access that. Not everyone needs to either, right? I think that's also really important to recognize. But I think parents can do this in small ways. They don't necessarily have to meet with a psychologist, right? If you're doing things like, you know, gardening or tours around the house or activities that you love, you know, going out for a walk, you know, you can talk about those things. You can share those things. You know, I'm having a bad pain day and here's how I'm coping with it. You don't need to meet with a psychologist to be able to do that, but really focusing on the things that are helping you to cope well and function well in your life will be beneficial for your kids to hear.

Evans: It could be that not hiding your pain is fairly pertinent to that situation.

Birnie: Yeah, I think it depends how you show it, right? I think there are ways we can show pain that can be unhelpful, whereas there are ways that we can show we're dealing with pain in more helpful adaptive ways, and I think being able to show the ways we're dealing with pain in adaptive ways, helpful ways where we're still able to function and engage in life are really powerful. If all your child sees are challenges, difficulty functioning, difficulty engaging in day-to-day life. I think that can make it hard, especially if they the child has pain themselves. I can have pain and still get out and engage in in daily life.

Evans: That's doctor Katie Birnie, clinical psychologist and assistant professor at the University of Calgary in Canada. In every addition of *Airing Pain*, I'd like to remind you of the small print that whilst we in *Pain Concern*, believe the information and opinions on *Airing Pain* are accurate and sound based on the best judgments available, you should always consult your health professional on any matter relating to your health and well-being. They're

the only people who know you and your circumstances, and therefore the appropriate action to take on your behalf.

Evans: Now it's important for us at *Pain Concern* to have your feedback on these podcasts so that we know that what we're doing is relevant and useful, and to know what we're doing well or maybe not so well. So do please leave your comments or ratings on whichever platform you're listening to this on. Or, of course, the *Pain Concern* website, which is www.painconcern.org.uk. This will help us develop and plan future editions of *Airing Pain*. Pain is sometimes described as the unwelcome guest in the house and no one invited it in, but the whole family has to learn to live with it. Last words in this edition of *Airing Pain* to Katie Birnie.

Birnie: When we talk to youth living with pain and their families about this, the example that's often shared is how you know a child may talk about their pain, or parents may ask a lot about their child's pain at the end of the day, and then that can drive the whole conversation that evening. The whole conversation over the evening, the dinner table can become about the child's pain, and actually we were talking earlier about identity and teenagers developing their identity. We want youth to see themselves as more than their pain, right. That's so important. People are whole people. They have other interests, activities, joyful parts about who they are as well. And so if we shift and say we're going to talk about pain for this period of time, but we contain that, and that instead of me as a parent asking my child about their pain instead, maybe I ask one question about that. But I also asked how was your school day? What are you interested in today? You know, did you speak with any of your friends? What would you like to do on the weekend? We talked about all these other things that are part of life doesn't mean pain is not there. But it shifts the focus. The focus is not on pain and our life as a family or as a, as an individual, being defined by pain. Pain is a part, but it's not the whole. And I think that's really important for all of us, but particularly for families.

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Transcribed by Owen Elias

Contact us:

General enquiries: info@painconcern.org.uk

Media enquiries: editorial@painconcern.org.uk

Pain Concern Helpline Telephone: 0300 123 0789

Pain Concern Helpline Email: help@painconcern.org.uk

Office Telephone: 0300 102 0162

Registered Charity no. SC023559. Company limited by guarantee no. SC546994. 62-66 Newcraighall Road, Edinburgh EH15 3HS