

Painful Bladder Syndrome (Airing Pain prog. 88)

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 of Airing Pain has been supported by a grant from the Women's Fund for Scotland.

Pat Brown: The symptoms were as if every step I took, someone was stabbing me with a knife up my vagina. There's no other way I can explain it.

Jennifer Hayes: All you can really do, because you need to be near a toilet and it's so painful and you feel just generally so unwell, I sit on a hot water bottle and just read and watch telly.

Pat Brown: ...and then the pain radiated out from there and I couldn't sit at all, I was in pain all the time.

Paul Evans: Interstitial Cystitis or Painful Bladder Syndrome is a poorly understood bladder condition that causes long-term pelvic pain and problems with urination. The charity, Bladder Health UK, estimates that 400,000 people in UK live with the condition - roughly 90% are women and 10% are men. Anne Cameron is a coordinator for Bladder Health UK in Scotland.

Anne Cameron: It's an abnormality probably in the bladder lining. At the moment, the cause of it isn't known it could be autoimmune or allergy related, in some people it tends to come along with other disorders like Fibromyalgia, bowel disorders, migraines. Some people may have obvious abnormalities in their bladder under cystoscopy; other people, it's not so obvious. But it generally causes or can cause pelvic pain, which can be really quite significant, urinary frequency, difficulty voiding urine, emptying your bladder fully or going for long periods, and quite a lot of other pain issues with, say, pain in your legs, various different areas in your pelvis. It does tend to vary quite a lot, but at the moment the cause isn't known, and there's no treatment that cures it and there's no treatment that helps everyone.

Paul Evans: Now, you were a nurse?

Anne Cameron: Yes.

Paul Evans: Did you have this?



Anne Cameron: I had it when I was nursing latterly, yes, and it gradually worsened to the extent that I found work extremely difficult, persisted in working, despite the advice of my consultant, was told that I shouldn't have been working, and then I eventually went on to have surgery which restricts me to what kind of job I can do. And I couldn't go back to nursing because my job was too heavy, so I'm now medically retired.

Paul Evans: Anne Cameron, coordinator for Bladder Health UK in Scotland. Jennifer Hayes has had interstitial cystitis for 2 years.

Jennifer Hayes: Well mine actually started with a bout of traditional, bacterial cystitis, and I've had that on and off all my life since I was 17. And it's always cleared up by antibiotics. And then just less than 2 years ago the antibiotics didn't seem to clear it up, and I repeatedly went back to the doctor and said 'It's not gone away' and they would do their tests and they would say 'But it has gone away'. Then we kind of got into a loop, and I was eventually referred to see a specialist but that took 9 months and by then it started to improve a bit. Of course, since then it's recurred so it's just a viscous loop really.

Paul Evans: I suppose, bladder problems, it's not something that you shout about or that you really want to make known to people?

Anne Cameron: No it's not, but I found latterly, when I was particularly trying to work, that I had to – I didn't have any option. Although you could say to your workmates 'I'm not feeling very well, I've got a headache' because of where I worked - I was in a ward - and there were no toilet facilities in the ward, and it started to become obvious to some staff. And at times you do have to tell people because when your diet get restrictive, when your fluid intake starts to get restrictive at times, or you're toilet mapping all the time, you kind of find maybe a lot of people that you've been in contact with a lot of the time, family, friends, all that, becomes very difficult.

Paul Evans: Anne mentioned the term 'toilet mapping' - what does she mean Jen?

Jennifer Hayes: It's sort of keeping a record of how often you go to the toilet, how much, you might measure what you've voided, because sometimes the bladder doesn't empty properly so you have to keep a record of how much fluid is going *in*, how much fluid is going *out*, how often, how you feel, what pains are involved in that.

Anne Cameron: I had quite a lot of intravesical treatments and at that point you have to chart-



Paul Evans: Inter- what treatments?

Anne Cameron: Basically treatments passed by catheter into your bladder to try and coat your bladder. And at that point they need to know how often you're going to the toilet, what problems you're having, what pain you're having. But the toilet mapping is also this thing in the back of your head if you're going out you need to know where all the toilets are in case you have to rush. And you can get to the point where you can be quite obsessed about it at times. Travel's very difficult: being on a motorway is an absolute nightmare, if there's a lot of traffic and you can't get off to toilet that you know is a mile up the road.

Paul Evans: What sort of issues do people who come to your support group bring with them?

Anne Cameron: The younger ones a lot of the time it's managing work, managing a kind of normal life. I'd obviously been married for a long while and I'm quite lucky my husband's quite easy-going, but it does put an awful lot of strain on your relationship at times. I certainly felt an awful lot of guilt and I know that there's maybe younger members in the group that perhaps would like to have families and all this kind of puts that up in the air. So that must be even more difficult for younger people you know, relationships and things like that.

Paul Evans: Explain why it puts it up in the air.

Anne Cameron: If you were to decide to go ahead and have a family, you don't know how that's going to affect the interstitial cystitis, if it's going to make things worse. But it's very disruptive to your life: I worked night shift for years but I quite often couldn't sleep when I came home during the day – it was quite common for me maybe to only get a few hours' sleep one night a week, type thing – which is very disruptive if you've got somebody, a partner, a family at home who are going out to work the next day. You know that you've kept them awake because you've been back and forward to the toilet all night. Certainly in my case, and I think it must be quite common a lot of the time, I use a separate bedroom to avoid disturbing my husband. I think quite often feel that they find that a bit hurtful.

Paul Evans: So what do you tell the young girls who come along to the support group with interstitial cystitis who are thinking about starting a relationship?



Anne Cameron: We only really have one younger member in the Glasgow group at the moment. There's another couple of members who are already in relationships and I think quite a lot of them have read up quite a bit beforehand.

Obviously things have been discussed, not so much about preventing pain in the first place, and not purely through relationships, but perhaps things that other members have found would ease their pain. Everything isn't the same for everyone. Some things suit some people and wouldn't be at all helpful to others. A lot of it's a very personal type thing, and a lot of its kind of a trial and error to see if there's anything that you would possibly find helps you.

We had a talk from Pain Concern and pacing was mentioned; that's something I've tried to do for quite a long period of time, and sometimes that's something that I feel you have to try and fit into a relationship as well.

Paul Evans: Explain that.

Anne Cameron: Well, obviously I've been married for years I'm not in a new relationship or anything like that, but if I thought I was going to be intimate I wouldn't the 2 or 3 days before do anything that was too active that I think would perhaps exacerbate things. I would have watched when I was working, I would have monitored how tired I was or how I was feeling at the time, and I certainly wouldn't have planned to have gone and done anything very adventurous the next day.

It's not just with intimate things; if I'd wanted to do, say, anything outside or a hobby that I liked, you tend to find that you have to work out what you want to do and then rearrange things either side of it to enable you to do that. [to Jen] You've probably found that at times?

Jennifer Hayes: Yes, you want to do some planning but your plans can often very easily go awry. But you do need to sort of protect yourself and slow down.

Paul Evans: Pacing is very difficult isn't it?

Jennifer Hayes: Very! And it's almost like needing a crystal ball as well. And when you feel that you can do something the temptation is of course to just go ahead and do it.

Paul Evans: But you say sort of 'Plan 2 days ahead', or 'Maybe you could plan 2 days ahead' if you want to be intimate with your partner – that is very difficult for a young relationship.



Anne Cameron: Yes, I think it is. And I think that's why so many people probably end up feeling very guilty and being hard on themselves, much harder than they really should be. But there's always this feeling that you're letting someone down. I would imagine particularly in an early relationship with younger people it must be very difficult.

Paul Evans: What are the treatments? If there are treatments.

Anne Cameron: There are various recognised treatments: none of them are cures, they don't all work for everyone, [in] some people they may worsen their pain. Quite often initially, if you have a cystoscopy to attempt to diagnose interstitial cystitis you may also have a hydrodistention, which basically stretches your bladder with fluid under pressure. It's not 100% sure why that works or how that works, but it's probably to do with damaging nerve endings so you're not feeling so much pain. That's certainly a treatment I had and I wasn't perhaps very keen on the idea, and the logic behind it didn't seem quite right to me, but unfortunately sometimes you don't really feel like you've got any option.

There's also a various range of bladder installations which I have. They're usually weekly treatments that run for 6 weeks and may be repeated every few weeks depending on your response to them. Most of them are based on hyaluronic acid, which didn't concern me, but the sort of older treatment is DMSO and it's based on a bi-product from the wood industry – like, paper and wood – and it's a glue-type substance, which I wasn't keen on, but that's one of the main treatments.

There's only really one oral drug which is prescribed for this, but that's on a named patient only basis and your consultant has to prescribe that for you. That can be quite difficult to get depending on your consultant and which [NHS] trust you're in. You usually have to take that for about 6 months before you start to notice any difference.

In America I think for several years they've been doing what they call rescue remedies, which has bicarbonate of soda and various things, an installation that they put into the bladder. As far as I'm aware that wasn't available in Britain until quite recently, I don't know how widely it's being used in Scotland, although I know there are some areas in England where I know it's being used. But that's to relieve the pain immediately rather than a long term type thing.

There's dietary advice, some people may take antihistamines, there's probably quite a lot of people who unfortunately don't get the chance maybe to go to a pain clinic and are on morphine and things like that. I don't know that that generally always helps people, certainly in my case I take gabapentin and amitriptyline. It kind of tends to vary perhaps which consultant you see, some of them obviously have different ideas and there is a wide range of particularly antihistamines, I think, that people try. There's obviously quite a lot of herbal things and there's quite a lot of supplements which are suggested, but I think sometimes you've got to be careful because you could end up with this list of things as long as your arm and you don't really necessarily know what's helping you and what isn't.



Paul Evans: Anne you were saying you had a procedure – an operation – to help you out?

Anne Cameron: Yes, I had what's called a continent urinary diversion with Mitrofanoff. Basically my bladder had been so badly damaged and had such small capacity I was more or less living in the toilet and there was no other treatments available to me. This was my last option. So I ended up having surgery, I was in hospital for about 4 weeks. I had my bladder, not removed I had it disconnected because of issues with blood vessels, and I now have a section of bowel which is internal and which is now a reservoir for urine. I have a very small stoma, which I catheterise about every 3 hours, and unless I have problems in the future I'm hoping this will be a life-long thing. Although I may in the future have to resort to a urostomy and wear an external bag. It has benefitted me hugely in some ways, but in other ways can be quite difficult because it's not a commonly done procedure. My GP doesn't really have any awareness about it and that can make things quite difficult if I have any problems. Once I eventually had my first cystoscopy about 4 years after I started going to my GP I got a definite diagnosis at that point. Up to that point, I'd basically been told 'Oh you've got IBS, get on with it. It's in your head.'

Paul Evans: Anne Cameron of Bladder Health UK. And I think this is a good point in the programme to remind you that that whilst we in Pain Concern believe the information and opinions on Airing Pain are accurate and sound based on the best judgements available, you should always consult *your* 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 back to Anne Cameron was saying about being made to feel that the pain was all in her head. It's a recurring theme with the people I speak to who live with chronic pain conditions. However, it's not to say that that the power of the mind isn't a fantastic resource to help manage one's pain.

The acronym EXPPECT stands for Excellence in Pelvic Pain and Endometriosis Care and Treatment. The EXPPECT Pelvic Pain Service is based in Edinburgh's Royal Infirmary and it consists of a multidisciplinary team, including; a consultant gynaecologist, a consultant in anaesthesia and pain medicine, a specialist nurse, an acupuncture therapist, a psychiatrist and clinical psychologist Dr. Shona Brown, who leads the pain management programme there.

Shona Brown: There's still a lot of misconceptions about psychology's role particularly in pain management and I think I always start consultations off with women by saying it's not because we



think the pain isn't real, or in their head. But we know that living with pain as a long term condition can be incredibly stressful, can impact what people can do, and that can have a knock on effect to their mood. And it's all about trying to help people live well with long term conditions.

Paul Evans: And one of those people who's been living with her long term condition, that's pelvic pain for 5 or 6 years, is Pat Brown.

Pat Brown: I'm in pain, it's chronic, it's neuropathic, and I think it started because I had lichen sclerosus. And once I was treated with steroids for that I seemed to have a reaction to it, and was left with this pain that I just had to try to deal with. And wasn't dealing with at all. The symptoms were as if every step I took, someone was stabbing me with a knife up my vagina. There's no other way I can explain it. And then the pain radiated out from there, and I couldn't sit *at all*.

It seems quite simple to say 'I couldn't sit down' but that affects everything in your life – you can't go out and socialise. Y'know I always joked to say I could lie down with my legs up in the air all day but other than that, I couldn't do anything! And then as the medication increased, and I'm not sure if it was the medication or myself, I began to get more panic attacks and have night terrors, and couldn't sleep either. So I was in a state both physically and mentally that I thought – and I know it sounds dramatic – but I thought I just could not continue, like that. And I was so lucky that my GP referred me to Shona, and I attended Shona's class for 12 weeks, so it was 6 sessions.

The crazy thing is I think I was in so much pain and so panicked about it, I couldn't see a way out of it. And I now wonder why I didn't look at other things I could've done. But at the time, I wasn't able to.

Paul Evans: Is that a common story?

Shona Brown: Yeah, and I think the nature of pain, it's so completely life altering and I think people feel really stuck. I think our society is very geared up to the medical model, y'know: we have a symptom, we expect to go to a doctor, for them to give us a diagnosis, a treatment, and that we will then be cured. And, I mean medicine is amazing and for lots of things it works very well, but we do know there's some times that it just doesn't work that way, and I think lots of the women that I see feel very stuck and very hopeless and not sure where to turn now. They feel quite on a path of trying to see a different doctor, get another opinion, another medicine, and I think sometimes it can feel a bit of a relief to know that there's something else that can help, another type of approach, and to look at some non-medication strategies.



Paul Evans: So at what point were you introduced to the idea of seeing a psychologist, Pat?

Pat Brown: I didn't even know I was going to see a psychologist, because my GP said she would refer me to pain management at the hospital, and I did say at the time 'Please refer me to someone that will actually help' and so I was referred to Shona's clinic. When I got there and I had 2 one-to-one sessions with Shona, first of all I just cried more or less all the way through it.

Initially I wasn't sure of where this would take me, but actually I was really pleased to speak to someone. And I think with neuropathic pelvic pain it's very isolating, too. You can't actually go to someone and say 'Well, y'know, my bum's really sore' or 'I can't sit down', you can't – well I never felt I could. I live alone, so I could speak to my son and 1 or 2 people, but generally, even now, maybe 5 or 6 people know I have this condition. I think it's an embarrassing condition for a woman and woman maybe of my age, but I was very isolated as well. So I was happy to speak to Shona, not really having any expectations. And she did mention the first time, or maybe the second time, we met, would I think about trying mindfulness. And I said to her I was be too old and cynical and I wouldn't be doing that, y'know, I wasn't really sure of what I was entering into.

Paul Evans: It's a huge leap, isn't Shona: you go to the doctor to be fixed. The doctor fixes, you are fixed. So it's a huge leap to come to someone like you

Shona Brown: What always amazes me is the bravery of people coming along, and I'm asking really personal, intimate questions, and how open people are. And how open minded they are. And I think maybe it is a reflection of people feeling they haven't got anywhere else to go and they're willing to give it a try, but you know, I think that's great from my point of view as a pain psychologist that people come with an open mind, willing to try things out. I think that's sometimes part of the work we do as pain psychologists, is trying to help people start to come to terms with the process of adjusting to the fact that this might be persistent, and maybe a cure a cure isn't going to be coming along any time soon.

Pat Brown: The first session that Shona did was actually about understanding your pain and looking at the actual, physical, what pain is. And I suppose, in a crazy way, I had never thought of that. I think I was in the model of going to the doctor and getting it fixed. So I think you build up confidence in the group, and then to be quite honest I was very, very desperate and I would've tried anything. If I could have stood on my head for half an hour every day and that would have got rid of my pain I tell you, I would have managed it. So I was willing to try everything that Shona



recommended. I didn't *do* all of them, but I certainly looked at them, tried them out and thought 'does that fit for me?' and through that managed to develop some strategies that help my pain.

Paul Evans: What sort of strategies?

Pat Brown: Well, the first thing Shona gave me, because I was so desperate when I saw her in the one-to-one sessions, she gave me a CD of tracks of relaxation. At first I listened to all of them, and then there was one which was a very straightforward one of tensing and relaxing – nothing, y'know nothing [complicated] – but I decided that I would do that every night before I went to sleep. I'd go to bed and I would listen to the track with my earphones on. And I did that, and I have to say, before I even started the pain management course, the night terrors went. I still didn't always sleep well, but maybe it was also the fact that I felt I was doing something, you know, whatever it is it was *something* I was doing. I remember saying to Shona in class when we were in the group, I was going to do this every night whether I felt great or bad, no matter what, and it would be my sort of security blanket. And I'm still doing it 2 years later, every night. Wouldn't matter if I went to bed at 3 in the morning, I couldn't go to sleep before I did this relaxation tape. So that was one strategy I've kept.

Other strategies *are* doing mindfulness every day, and exercise. Which, you know, I'm not very keen on exercise – I wouldn't say I was an active child or adult – but now I do exercise, especially yoga. So that's another one. And actually just trying to have a much more positive mindset when it flares up at its worst, to think 'I've been here before and it *has* got better, and if I can really *really* distract myself then I will have even 5 minutes without pain, which could end up being an hour'. The first time I did a yoga class, I didn't have pain the whole of the rest of the day. Sometimes now I do yoga and I've not got pain for an hour. But I never come away from a yoga class in pain.

Paul Evans: The pain management programme you said it's a 12 week programme. What happens when that 12 weeks is over? When you're on your own?

Shona Brown: That's something we talk about as part of the group, and we start to prepare people to think about what are the next steps, because I'm well aware that doing a short term group it's not that at the end of that group everything is exactly how the person would like it to be. It's introducing them to some coping strategies and the *start* of a process. So then thinking about what the next steps are, and what there is, perhaps third sector organisations that might support that. I always mention Pain Concern and Airing Pain to give people some of the things that are out there that they might want to link in with. Things like vulval pain we'll mention the Vulval Pain Society website, get people thinking about what other sources of support there are. And yeah and acknowledging that it



can be a bit of a scary time. I think if people have made progress they sort of attribute that to coming along to the group, and I often think about it quite differently. I think actually it's what the people who are coming along are doing, it's them who are making these changes – we're just giving them some ideas. So discussing some of that I think can be helpful too.

Paul Evans: That was psychologist Dr. Shona Brown of the Pelvic Pain Service in Edinburgh. And some of those third sector organisations: of course we at Pain Concern can be found at www.painconcern.org.uk she also mentioned the Vulval Pain Society and its web address is <http://www.vulvalpainsociety.org> and the patient support charity, Bladder Health UK <http://bladderhealthuk.org/>

Here's their coordinator in Scotland, Anne Cameron's advice for those who think they may have interstitial cystitis, but aren't sure. What's the first step?

Anne Cameron: I think I would look at their symptoms, advise them to think how long this has been going on for, the problems that they're actually having. Obviously going to their GP. If they're looking online, obviously look to sites like Bladder Health UK. Be careful at times looking online because it's like everything else you can get a lot of bad advice, and sometimes it's very easy to read things and think 'Oh I might try that or I might do this': everyone's entitled to different views but look for information via a reputable source.

If they feel this is possibly what they've got, perhaps do a wee bit of research and if you decide to go to your GP explain your symptoms and explain to them why you think you have this. But to be honest, [being] realistic about it, you might find you have to push quite a bit or it's something that you have to persist with.

Paul Evans: So you have to be positive with your GP?

Anne Cameron: Yes I think so. Sometimes it's difficult to be, but I think if you perhaps go in negatively with a big list of symptoms and you're really stressed about it in front of them, I don't always think that benefits you best. In all fairness probably at times I was a bit like that because I found it took so long to get a diagnosis. But contact Bladder Health UK, phone them up: they've got loads of resources whether it be books or whether it be advice leaflets. You've also got the capacity to ask questions, they've got a medical panel of urologists and things can be ran passed them. There are quite a lot of options but just be careful where you look for the advice.



Paul Evans: And you were saying about seeing your GP. Pain Concern publish a document about managing your consultations as well, and I think one of the words of advice is that you should go in with a *short list*: not a list of 24 things that you think might be wrong with you.

Anne Cameron: Yes.

Paul Evans: And just tell me again, support groups: how important are they, Jen, for somebody starting out?

Jennifer Hayes: I think they're tremendously important, because very few people mention the word 'interstitial cystitis' actually, my doctor has never called it that.

Paul Evans: What does he or she call it?

Jennifer Hayes: Irritable bladder syndrome. But when I went to see the specialist at the hospital, all the support staff said 'It's probably interstitial cystitis, have you ever heard of that?' But I had already heard of it, because when you start looking up bladder conditions it leads you, and then you lead and you look at that and you think 'Oh that's it, that's just exactly what it is'.

Paul Evans: That was Jennifer Hayes. Now, we referred earlier to *endometriosis*. If this is something that affects you, then listen to Airing Pain edition number 42, which focuses on endometriosis.

You can download that and all editions and transcripts of Airing Pain from Pain Concern's website, and once again it's www.painconcern.org.uk.

Now, to end this edition of Airing Pain, you'll remember that Anne Cameron mentioned that her GP had thought her pain was all in her head.

Anne Cameron: When I went back and just happened to see the same GP again after my surgery I think he was a bit taken aback. He obviously realised you don't end up going through major surgery and being in hospital for a month for something that's in your head.

Paul Evans: The plus point there, I guess, to fill one's glass half-full, is that now your GP knows what the condition is.



Anne Cameron: Well I hope so, and I hope it's something that would be to the advantage of other people going in with the same kind of symptoms. I hope they would pick up on it now, rather than people being in this situation where it goes on for years and you're unable to get any help. I hope what I've gone through would perhaps be of benefit to someone else.

Contributors:

- Anne Cameron, retired nurse and Scotland Coordinator for Bladder Health UK
- Jennifer Hayes, pelvic pain support group member
- Pat Brown, patient at EXPPECT clinic at Edinburgh Royal Infirmary
- Dr Shona Brown, clinical psychologist at the EXPPECT clinic at Edinburgh Royal Infirmary

More information:

For more support and information on living with pelvic pain, visit:

- <http://bladderhealthuk.org/>
- <http://www.pelvicpain.org.uk/>
- <http://www.expectedinburgh.co.uk/>
- <http://www.vulvalpainsociety.org/>
- <http://www.painconcern.org.uk/>

