

***Airing Pain* Programme 42: Endometriosis and Support Groups**

Paul Evans visits an endometriosis support group in Belfast, and interviews founder Anna Jamieson and guest speaker, gynaecologist, Dr David Hunter. Dr Hunter discusses the research about how endometriosis develops and people living with the condition describe their experiences in-depth, including the impact upon personal relationships with family and friends. Members of the support group talk of their immense relief at finding people with similar stories to share. We hear about the difficulties in diagnosing endometriosis – often mistaken for other conditions such as irritable bowel syndrome – but also about some recent improvements to its management and the crucial role of sympathetic healthcare professionals. We also learn more about surgical treatments and their likely prognoses, including hysterectomy, and we hear about the physical, psychological and emotional impact of such surgery.

Paul Evans: Hello and welcome to ***Airing Pain***, a programme brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain. This edition's been funded by the Big Lottery Funds award for our programme in Northern Ireland.

Nuala Campbell: Every single month I was brought into A&E and every month I was just told that 'You have a low pain threshold. This is what it's going to be like to be a woman, you better get used to it. There's nothing wrong with you, it's just wind.' I was kind of treated like I didn't know my own body.

Evans: Now there are two aspects to today's edition of ***Airing Pain***: one is to explore a condition that affects 1.5 million women in the UK, and the other is to see how belonging to a support group can be a valuable aid to managing any chronic condition.

Earlier this year, I went along to the monthly meeting of the endometriosis support group in Belfast. Their guest speaker, gynaecologist Dr David Hunter, was conducting a question and answer session.

Dr David Hunter: Endometriosis is a chronic progressive condition which can develop at any stage throughout a woman's reproductive life. It's more common in women in their thirties and forties, but can present much earlier, and when it presents earlier it's often very

severe and aggressive. So it's a disease that affects extra-uterine organs, the ovaries, the side walls of the pelvis, sometimes the bowel, and the area at the top of the vagina – the pouch of Douglas. The symptoms that it causes are chronic pain, pain with intercourse, pain with bowel motion and sometimes crippling menstrual pain.

It's often associated with a very similar condition called adenomyosis, whereby the lining of the womb, rather than growing outside the womb or within the lining of the womb cavity itself, grows into the muscle wall of the womb. That's a condition that presents a particular management difficulty because the only truly effective treatment for this condition is hysterectomy. Endometriosis per se, being an *extra*-uterine disease, can be treated by excision of the endometriosis and conservation of the womb. But when adenomyosis is present the improvement in pain scores is often much less, in the absence of a hysterectomy.

Evans: Dr David Hunter. And – dare I say it – something of a knight in shining armour for the Belfast endometriosis support group's founder and driving force for 27 years, Anna Jamieson. The condition, as I mentioned earlier, affects at least 1.5 million women in the UK.

Anna Jamieson: We like to think of it as 1 in 10, because to us that means an awful lot. If you think that [for] each one of us here, there's another nine ladies out there who have endometriosis. One patient has written 'I feel like I am being hollowed out by a brillo pad.' I don't know if anybody else has had that experience, but I know / felt as if somebody was running a grater over my insides. One and a half million, 1 in 10 of us, suffer with endo and the same number of ladies suffer with diabetes, and yet look how widely diabetes is known about!

Seventy-three per cent of women have reported relationship problems: 10% within ordinary friendships; 11% say it has caused breakups in friendships or in relationships; 11 % find it difficult to look after children; and 39% say that it has caused significant problems between them and their partner – and that again is very sad. But in this little group I don't think we allow that to linger – do we girls? We don't. We are an upbeat group, we like to think that there are better days coming, and with the help of Dr Hunter who's been absolutely fantastic to the girls here in this group. I think he knows more about our insides than we know.
[Laughter]

Evans: Just tell me in simple terms so I can understand this: the tissue from the womb actually grows, spreads, outside the womb – is that right?

Hunter: Yes. There are a number of theories about how endometriosis develops, and the oldest of those theories is called Samson's theory: at the time of menstruation, in addition to menstrual effluent being expelled through the cervix, some of the menstrual effluent is expelled through the fallopian tubes into the tummy cavity or pelvic cavity. In a number of women that tissue retains the ability to survive and plants into the tissue that lines the tummy cavity and then becomes viable. It then responds to the hormones that the ovaries produce on a cyclical basis and obviously each month bleeds, causes inflammation and may cause adhesions or scarring which tends to make things stick together.

Evans: Can it spread *beyond* the abdomen?

Hunter: Yes. One of our patients this evening had [this] disease very close to her lung. It can also be found in abdominal wounds or actually within pulmonary tissue, and that is *not* in keeping with Samson's theory of development of endometriosis, which is one of the reasons why other theories have been postulated.

Linda Harris: I'm Linda Harris and I've suffered with endometriosis for about 8 years now. Mine caused extremely severe pain, with vomiting, with sneezing, with coughing, with hiccupping... And I had already suspected at that stage myself that I had endometriosis – in my diaphragm – and subsequently I found out I had it quite extensively in my pelvis and in part of my body wall and my diaphragm as well.

Evans: With so extensive a spread, what's the treatment for that?

Harris: Initially to help diagnose it Dr Hunter did an MRI on the pelvis and again he knew that... he didn't think that the endometriosis on my diaphragm was likely to be visible on the MRI, so they found it extensively on my pelvis but couldn't see anything on my diaphragm; had that removed and was sent home hoping that the pain in my side was sort of maybe referred pain or that hopefully the surgery would improve that, but 3 weeks later the pain in my side was just the same – the surgery hadn't helped *that* pain. I had had some pelvic pain before but really nothing compared to the pain in my side so I went back and then got a further MRI which showed up the endometriosis on my diaphragm and in my body wall as well. Then I got referred via a cardio-thoracic surgeon to a liver specialist who did my surgery 6 months ago and my life has improved beyond recognition.

Hunter: The thing with your suspicions was you *knew* what you had long before I diagnosed it.

Harris: Yes. Yes.

Hunter: And it took a little bit of a while for me to get to the bottom of you.

[Everyone laughs]

Harris: Yes. The only thing I would say is that Dr Hunter at least *believed*: I think that was probably the most important thing after so many years for somebody. It may have taken a bit of work to get there and it certainly wasn't a straightforward presentation or maybe a more normal presentation, but I suppose all I would've asked was for somebody to listen to me and to *believe* my symptoms rather than maybe, really, probably dismissing them for a long time. So I think, yes, with endometriosis it's not always simple by *any* means, but to just believe in your patients and, you know, together you can get there and the improvement in my quality of life, I would say also for my husband and my family: the improvement in his quality of life is really beyond belief. He would never really have known me as a well person, and for him not to be running about at three in the morning with a bucket for me to be sick in and waking up has been a huge help for both of us. So thank you very much to Dr Hunter and the team.

Hunter: One of the most important things that I've learnt in my medical career is the importance of listening. People know their own bodies. If you listen carefully then people will tell you what's wrong. There's nobody who can diagnose endometriosis without either looking at it directly or having a biopsy specimen confirm it, but patients will often direct their clinician to their diagnosis, and it's listening to the direction that I find very important. And listening as well to what the patient wants from her treatment because not everybody wants the same thing. And again, another blunt question that I ask sometimes is 'What do you want to take from your treatment?': because we can't always fix everything.

Nuala Campbell: I'm Nuala Campbell, I'm 30 years old, and I have been suffering from endometriosis since I was 15. It affects everything, it affects – like I have chronic fatigue along with endometriosis, so it affects my ability to do a lot. I can't go out and do all the social things that someone at 30 years old might want to do. I can't have children, I was told around when I was 26 that I would never have children naturally. At 15 I was being brought to hospital either by ambulance or by a parent who was totally freaking out, so every single month I was brought into A&E.

Evans: Every month?

Campbell: Every month, every month. And I was just told that, 'You have a low pain threshold, this is what it's going to be like to be a woman, you better get used to it', you know, 'there's nothing wrong with you, it's just wind'. I was kind of treated like I didn't know my own body. Even after I had my first laparoscopy to diagnose, they drained a lot of internal bleeding from my pelvis, so I lost around a stone and a half of weight when I came out of surgery, and they still didn't diagnose me with endometriosis; they let me go home. It was another 3 years after that before they said it was endometriosis.

Robyn Atcheson: My name is Robyn Atcheson, I'm 24, and even my doctor was so convinced that there was nothing wrong with me that whenever I had the operation I was told, on my way into theatre, that there wouldn't be anything wrong with me, that I would wake up and I would still not have an answer [Laughs]. I should point out that I asked for this operation specifically to get an answer, whether it be positive or negative. And whenever I came round from the operation and it turned out that I did have endometriosis, there was actually too much of it to remove at the time, so I had to wait a further 6 months to get it removed. I'm still recovering from that, it's only been about 6 or 7 weeks – 7 weeks now. But just having that diagnosis makes a world of difference. You can tell people, 'This is what I have that's wrong with me', it's not just a generic 'I'm in pain a lot of the time and nobody knows why.' This is my condition, you can look it up on the internet, you can read blogs about it, you can look at what other people are saying about it and people can then start to understand and get a bit of an awareness of what it is that you're going through.

Evans: Do your friends understand?

Atcheson: The friends that I have now do. Whenever I first got ill, I have lost a lot of friends since then. You have to cancel a lot of social things, you maybe have to alter your lifestyle a bit, you can't do as much as you used to be able to. And some friends can't really see that whenever you look the same on the outside that there's something different that's happened to you that you're struggling with, maybe behind closed doors, behind the smile that you wear every day. For a condition like endometriosis, a gynae condition, it's not always the easiest thing to talk about and some people don't like talking about it. My best friend is a boy – it's been interesting educating him about it, but he's actually been one of the most supportive of my friends and he really tries to understand where I'm coming from. And he would be the one that would help me out the most: he would notice when I'm having a bad

day and would help me carry things or would walk me to my car and things like that. So I think that the friends that I have now are probably the truest friends I've ever had because they're the ones that know me, pain and all, and accept me for that.

Evans: Is diagnosis a problem?

Hunter: A diagnosis is very problematic, and there is a delay in diagnosis of 10 years on average between the onset of symptoms and diagnosis within the UK.

Evans: Ten years is an awfully long time.

Hunter: It's dreadful.

Evans: Why is that – just because it's a problematic diagnosis or because people have to wait too long?

Hunter: I think it's because the symptoms that women get with endometriosis tend to be non-specific and there isn't a single symptom or group of symptoms that patients would have that would prompt GPs to initiate a diagnosis and treatment. Fortunately, that is changing and GPs are becoming more aware. I spoke with a group of GPs just this evening and one of their primary concerns was when they should refer patients with chronic pain. So I think GPs are becoming more aware of the diagnosis.

Evans: So how could it be misdiagnosed, then? What other things could it be?

Hunter: We often see girls who are told that their periods are just as they are, that that is their lot. We see girls who are told that they have irritable bowel syndrome, and we see patients who've advanced quite far through an infertility, investigative network without having diagnostic laparoscopy to confirm or refute a diagnosis of endometriosis.

Evans: As a teenager, knowing that you have problems, what did it feel like to be told that you have wind, or 'You're a woman, get on with it'?

Campbell: Frustrating. You kind of lose the will a bit, you know? You're kinda, like, well, if that's right and this really is what it's like to be a woman, I don't want to be a woman anymore, I don't want... like, this is me until I hit menopause at whatever age. It's so disheartening to think that you're just going to be left like that for the rest of your life and you

just have to deal with it. So it's quite scary. It would depress you quite quickly if you didn't have the right people around you.

Evans: When did you start to have the right people around you?

Campbell: I suppose I did a lot of online research myself, and I only discovered this endometriosis group maybe 4 months ago –a I was never told about it by any GPs or any gynecologists, nothing. So I was part of endometriosis groups online and got to read a lot of stories from other women who were going through the same thing, so I got a lot of reassurance from that. Because when you're sitting in pain all the time you have thoughts and you think you're going mad, like I used to think 'I wish I could give this pain to someone else for a day, to see if it really is this bad!' or 'Do I have a low pain threshold?' and then you hear that all these women are thinking the same thing.

Evans: You say you've only been coming to this endometriosis group in Belfast for 4 months.

Campbell: Yes.

Evans: How important is a group – a physical group – rather than meeting online?

Campbell: So important. I really, really enjoy coming here. I look forward to it every month. It gets frustrating sometimes in life and sometimes you just need somebody to go, 'Yeah, I'm feeling the same way' and you're like 'Oh, great, I'm not alone!' And even just coming in, being surrounded by so many women who try to remain positive about the disease and do their best to kind of stay on top, it has such a lovely impact on your life and your ability to cope.

Louise: My name's Louise and I am new to this endo pals group. I just went last week, having read an article on endometriosis, and I got in touch with Endo UK, or Endometriosis UK, and saw that there was a support group nearby. I've been living alone with this for a very long time, so this is quite new to me.

Evans: Tell me how endometriosis affects you.

Louise: It, basically, is like somebody stretching my whole bowel area: actually as well as even below that – but as far up as my bowel area – like a huge elastic band to the point

where it's almost ready to break and then basically searing a hot poker over it. In fact I've fantasised at the time of going down to the kitchen and getting out a knife and literally just cutting a big square in my tummy and just lifting out this block of a problem, because it is just so excruciating. And I know the pain is so strong that I wouldn't actually feel it if I did that, because of the pain of endometriosis.

Evans: And how long have you had it?

Louise: I've had it for 22 years. I'm 34 now, and just like Dr Hunter said, it was about 10 years before I got diagnosed and I diagnosed myself. I saw it in *Company* magazine when I was about 20 and it said 'Period Pain Put Me in Hospital' – it was one of their front stories. I grabbed it from the shelf and I got in touch with what was then the National Endometriosis Society. They were able to give me a referral to somebody in my area here in Northern Ireland.

Evans: You've just joined this endometriosis support group in Belfast, this is your second visit – how useful is it?

Louise: I'm still taking on board everything that I have learned about endometriosis, so that is just mindblowing and I just think it's amazing to be meeting all these girls who have such a wealth of information but are so determined to promote endometriosis awareness and to actually try and improve the services that are out there. I wish, to be honest with you, I'd known about them – well, the second I had endometriosis, because I've lived in the dark with it for so long. And to be in a room where there are actually other people who have gone through that... I'm still taking it in, actually, but it does give me hope, and I know I'm not alone and I know that it means I can still manage to have a family at some point and maybe I can have a job: things that I had written off.

Evans: How many women are offered hysterectomies too early, do you think?

Hunter: I can only comment about what happens at my clinic. And obviously the choice to undertake a hysterectomy is a very big decision that a woman has to take in terms of fertility aspirations and loss of femininity – these things will have to be considered. And I know that women who have a hysterectomy younger tend to have a very high incidence of post-treatment mood disturbance (depression) because of regret about undertaking the hysterectomy. So, I can't give you a figure, but certainly we counsel women very thoroughly and don't rush to hysterectomy in most cases [Laughs]. We have a young lady here who

was unsure for many years, actually, about whether or not she wanted to have a hysterectomy.

Evans: There was a lot of laughter.

[Women laugh in the background]

Hunter: Mmmm! There wasn't a lot of laughter for many years.

Jamieson: There were a lot of tears the morning of the surgery, believe me.

Evans: [Turns to Jacqueline.] Do you mind sharing this? What you went through?

Jacqueline: From the age of about 15, I've been in severe pain and for many, many years, I was misdiagnosed with everything under the sun. I struggled for a long, long time, and I was one of the lucky ones: I had my family. The morning of the surgery, I still was in tears, but I am now 11 weeks post-surgery, and I'm pain-free for the first time in 23–24 years.

Evans: Can you explain to me what you struggled with?

Jacqueline: For probably 3 weeks of the month: severe, severe pain. Now I can sneeze without being doubled in two and have pain in my pelvis. I can straighten up and hold my children. My children don't have to say, 'Oh no, you can't do that because Mummy's belly's sore or Mummy's tummy is sore.' I can walk up the stairs on good days – there's not a problem. That pulling, dragging, horrendous pain is not there anymore and I'm just so thankful that, touchwood, it won't come back.

Evans: Does that mean that Jacqueline no longer has endometriosis?

Hunter: Well 90% of people who undergo the type of surgery that Jacqueline has undergone will remain disease-free at 5 years, and Jacqueline's case demonstrates very clearly that women who suffer with endometriosis don't fully appreciate the impact that their disease has on their quality of life until *after* they receive treatment. When they're better and they can look back, they realize how poor their quality of life was. People do accept it, because they've been told, 'This is your lot', and they accept that this is [their] lot. It's only after treatment, when life is better, that they can look back and say things were miserable.

Jacqueline: You get to a certain time – it builds up and builds up throughout the month, and

you get to a certain point where you say, 'I cannot do this anymore; I can't take this pain anymore'. Then you get a bit of release because you have your period and that sort of gives you a bit of release, and then it starts to build up again. The only other time that I was pain-free was [during] my three pregnancies, but I can honestly say I put off the hysterectomy from when I was about 28/29, and Dr Hunter didn't want to do it either because I was so young and I hadn't had my family. Now that I've had it, I just say it was the best thing – because I've had my family I can say that. I know others that are trying for it, [for whom] it's not the best option; it's not the right option, but for me, it has been.

Hunter: One of the first questions that I ask people when they come into the room is, 'Have you finished having your babies?' It's a very blunt question, but it helps to direct treatment. Jackie wasn't sure. So if someone isn't 100% sure, then we can't do a hysterectomy.

Evans: So what are the options for those people?

Hunter: Well the options then are either to treat surgically and conserve the uterus, and then add in some Antivert medical therapy, or just to treat medically by turning the ovaries off and effectively rendering patients temporarily menopausal.

Evans: But that is temporary?

Hunter: That is temporary. It doesn't work for everybody. And if treatment is discontinued about three-quarters of patients have a flare-up of their symptoms.

Jamieson: I set this group up over 27 years ago because when I had endometriosis and [was] facing a hysterectomy, like Jackie, I kept putting the hysterectomy off. Every time I was told in that room over there that I had to have a hysterectomy, I would come out and say to the nurse, 'I'm not going to have a hysterectomy.' So I set the group up because I was actively looking for somebody in the same situation. I just needed to talk to somebody and that is why this group was set up – just so that we could talk to one another.

Anyway, I set the group up, and one by one, we all came, and it was called the Hysterectomy Support Group in those days. And then one after the other after the other girl coming in was having her hysterectomy because of endometriosis, and she was in the same situation as I was, saying 'No, I'm not ready for a hysterectomy.' Please let me make you understand tonight that unless you are, you never have it. Anyway, we had to find a way around, supporting each other and supporting the girls who come in. I'm just looking tonight

at Jackie, and I can tell you the night that Jackie walked through the door there, another lady and myself had to go down to the door and help her into a seat. We were using the kitchen in those days – do you remember that? Jackie could hardly walk. Now look at her! I am a firm believer in the fact that if you can find somebody else to talk to, that is really one of the best things that you can do.

We are here because we have been helped. Carine and Lara...and Tracy's been here since she was 19. And I'll not tell everybody how old you are now; I know you. But Tracy came here when she was a 19 year old, having been told then that she would have to have a hysterectomy. Tracy, with David's help, was able to get through life. Tracy was really very, very bad. We shared the same GP. We have our meetings on a Thursday night, and I had to see him on a Friday for a blood test, and I walked in, and I said, 'Before I get this blood test, I want to tell you that there's a wee girl who comes to our group and her name's Tracy, and she really needs to see somebody else.' When Tracy went for a letter for a second opinion, she got it and she was able to go to Middlesbrough. When she came back a couple of weeks later, I went to visit her, and she said, [Gasps] 'I met this lovely young doctor and he's from Belfast!' [Laughter] That was David, and when he came over here and got his consultancy post, and even before that, [he] was always very willing indeed to come along and support us as we supported each other.

Evans: How important is it for *you* to meet patients like this in this informal gathering?

Hunter: I love coming along here. [Laughter]

Evans: And not just for tea and cakes? [Laughter]

Hunter: Not just for tea and cakes. [Laughter] I think it's great to get the feedback that we get from a group like this because we have patients here – some of the girls here haven't done as well as others. Some of them continue to suffer and it's good to have that feedback as well as the positive stories. And it's heartening for me to see the fruits of my labour because it's great to know that I can make a difference.

Evans: My thanks to David Hunter and the ladies of the Belfast endometriosis group for letting me sit in on their meeting. If you'd like to find a support group in your area, then check out the Endometriosis UK website, and that's at endometriosis/uk.org. My usual words of caution are that whilst we 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. 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 the previous editions of ***Airing Pain***, or obtain CD copies direct from Pain Concern. If you'd like to put a question to Pain Concern's panel of experts or just make a comment about these programmes, then please do so via our blog, message board, email, Facebook, Twitter, or pen and paper. All the contact details are at our website, which is painconcern.org.uk. I'll leave you with the ladies of the Belfast Endometriosis Support Group.

Member of the Belfast Endometriosis Support Group: I haven't been able to wear jeans in 4 years, and yesterday, I wore jeans for about 10 hours. It was the best feeling in the world, just being able to wear jeans, because I've been wearing loose-fitting clothing for 4 years, in fear that [jeans] will hurt me. I haven't reached the ultimate goal, which is to wear jeans while eating pizza, because eating cheese triggers my pain. It isn't a very exciting goal for a 24 year old, but to just wear jeans and eat pizza would be great.

Member of the Belfast Endometriosis Support Group: Anna, not being well herself, nor her husband, came up on the morning of my surgery, and she sat on the bed while I cried my eyes out. She was a lifesaver when I came here 15 years ago. She's never let any of us down. I just want to say thank you, and I'm sure the rest of the girls want to say thank you too. [Applause]

Contributors

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- Anna Jamieson, Founder of Belfast Endometriosis Support Group
- Linda Harris, Group Member
- Nuala Campbell, Group Member
- Robyn Atcheson, Group Member
- Louise, Group Member
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