

Airing Pain Programme 97: Sex and Chronic Pain

How chronic pain can affect both sexual and emotional intimacy, and remembering that communication is key.

This programme is supported by an educational grant from the Tillyloss Trust.

Along with food, shelter and clothing, sexual expression is one of the basic human needs. It allows us to express love and fulfils our need for human connection, but for the 14.3% of people in the UK living with moderately or severely disabling chronic pain, sex can be met with trepidation and anxiety.[1] This is understandable, as it is estimated that 75% of those that live with chronic pain experience sexual dysfunction.[2]

There can also be a certain amount of embarrassment in discussing chronic pain and its effect on sexual activity with healthcare professionals, especially if they don't have the skills to address these issues. This is why Pain Concern has updated its sex and chronic pain leaflet with authors Katrine Petersen, senior physiotherapist, and Dr Sarah Edwards, clinical psychologist, who specialise in abdominal pelvic pain at the Pain Management Centre, University College London Hospitals NHS Foundation Trust. You can find the leaflet on our website here.

*In this edition of **Airing Pain**, Paul speaks to Dr Edwards and Petersen about the major difficulties patients experience when it comes to living with chronic pain and managing sexual intimacy and techniques that can be used to combat them (you can find these techniques in our leaflet).*

Denise Knowles, family counsellor and psychosexual therapist working with relationship support charity Relate, speaks about her experiences of how relationships can be affected not only by physical pain, but by mental pain as well. She also stresses the importance of the distinction between 'sex' and 'intimacy'.

[1]The British Pain Society <https://www.britishpainsociety.org/mediacentre/news/the-silent-epidemic-chronic-pain-in-the-uk/>

[2] Robert Rothrock <http://painconcern.org.uk/sex-and-chronic-pain/>

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 is supported by an educational grant from the Tillyloss Trust.

Denise Knowles: Over the years that I've been working in this area, I never cease to be amazed at what a taboo subject sex still is between couples. You know, we're surrounded by sexuality and yet it's still a very difficult subject for people to talk about.

Evans: Persistent or chronic pain can impact on lots of areas of life such as work, exercise, socialising and mood. But its effect on sexual activity can be difficult to discuss, or even admit to by the person in pain and his or her partner. Difficulties and embarrassment can also be compounded when one's health care professionals don't have the skills and confidence in addressing sexual difficulties. With this in mind, *Pain Concern* has updated its 'Sex and Chronic Pain' leaflet. Its authors are Senior Physiotherapist Katrine Petersen and Clinical Psychologist Dr Sarah Edwards, both of whom specialise in abdominal pelvic pain at the Pain Management Centre, University College London Hospitals NHS Foundation Trust.

Dr Sarah Edwards: Most people who come to see us struggle to talk about [sex] either when we first see them for assessment or when we're seeing them for regular therapy sessions, either individually or in a group. So [*that's*] one of the reasons that we did the leaflet and we're also writing up a model that we've written on working with sex with people with chronic pain. We're writing it up for publication, partly just to publicize the whole issue, because I think people get very embarrassed, they feel quite ashamed, they feel quite shy about talking about it.

Of course, if they don't talk about it as an issue, it's *hard* for us as clinicians to help them. On the other side of the coin, as *clinicians*, we're often quite reticent to bring it up as an issue because we also feel embarrassed and don't quite know what to say or how to ask. So it's really trying to open up the conversation, I think that's the starting point.

Evans: I have to admit that I'm embarrassed as well. I'm a man well beyond my prime [laughter] but it is not a subject I would bring up anywhere outside my household or in front of you two.

Katrine Petersen: As a physiotherapist, I will ask people about various aspects of their lives, in terms of activity. So I'll ask them about sport, walking, sitting, going out socialising etc. and along that list of questions I have comes intimacy. So I ask about relationships and

intimacy and a majority of people are quite willing and relieved that someone's actually asking about the issues.

Evans: So, what are the issues, you tell me?

Petersen: Often, with chronic pain patients, well number one, they can be on a number of medications that means that sexual activity becomes much more difficult. At times, they don't even realize it's a medication that might be causing them to have problems with sex drive. It's not until you raise it and explain it to them, that they can actually do something about it, rather than worrying about it being another type of issue.

Then, of course, there's all the physical restrictions that people have when they have pain and things they want to avoid. Ultimately, it's just like any other activity, if something is painful, you want to avoid it. But over time, what we know is that people then start missing out on something that's a huge part of their life.

Evans: And I guess missing out on that, it puts huge burdens on a relationship?

Edwards: Hmm, I think it can put a relationship that might be under strain already, under even more strain. All of us hold kind of ideas or myths in our heads about how sex should be and that's often come from the media, from newspapers and soap operas, and everything else. So all those ideas about sex which should be *spontaneous* and *adventurous* and *three times a week* or whatever it is that you've read in the paper, and if people aren't living up to that ideal, they often feel that they can't really mention it. If they don't talk to their partner about it and sex just falls by the wayside, that can lead both partners to feel quite disconnected from each other.

What we see sometimes with people who aren't in a current relationship, is that they may assume that because they've got pain and sex is more difficult than it used to be, they put any idea of being in a relationship in the future on hold, that it's just not going to happen. That's such a big part of life that it's a real loss to shut oneself off from that possibility. We'll often help them to build up their confidence, so they can consider having a romantic relationship in the future, rather than thinking to themselves that that will never happen.

Evans: So how do you deal with that? Say somebody, well they don't have to be young, they could be middle-aged, they could be old and not in a relationship and holding back from a relationship, because they feel that whoever they get involved with, the partner will not be fulfilled, it wouldn't be a fulfilling relationship. How do you deal with that?

Petersen: I talk to patients about activity and it would be familiar to a lot of people who might have worked in pain, or who have been to see pain management clinicians - the idea of pacing and the idea of finding a baseline and then gradually building up. It would be familiar to lots of people, if they want to run a marathon, they're not just going to do a marathon - they kind of build up for it gradually. They will probably hurt somewhere along the way but that's a normal part of building up. So I talk to patients about how you build up to activity in the same way, when I talk about sexual activity.

If someone is not in a relationship, it's about establishing a baseline, what are they prepared to explore? So we do have to talk about words like masturbation and vibrators and stuff that patients can do themselves to work out their baseline - because if they do come across someone whom they might want to be in a relationship with, it's really important able to explain to them what can I tolerate, this is this is as far as I'm prepared to go at this point in time.

Of course, exploring those myths - just because you meet a partner who looks well, doesn't mean they don't have their own issues. It's surprising how many people do gradually start to realize that actually, a *huge* part of the population will have some form of sexual issue at some point in their life and that we *all* have to have strategies to deal with that.

Edwards: There's a very helpful approach called Sensate Focus, which is used in lots of different areas of sex therapy, which is basically a step by step building up of sexual activity, starting just with physical affection and then moving all the way up to penetrative sex, a lot further down the line. That works really well for people for all sorts of reasons, but again if you're in a relationship when you have a partner, you need to communicate about that for it to be able to work. That can be embarrassing, so sometimes people will show their partner some written information, like the new leaflet that we've done or something else - that's a kind of starting point to discussing something that maybe they haven't openly discussed before.

Most people's experience is that actually their partner may have had some worries themselves about why sex has decreased [such as] doesn't that person find them attractive, don't they like them anymore, is the relationship on the rocks? So *usually* they're quite reassured by the discussion, even if it is a bit embarrassing.

Evans: But when we talk about discussions, that assumes that couples are still talking to each other and that it hasn't gone beyond that point of anger, if you like, and frustration.

Edwards: Yeah, I think that's a very good point and there are all sorts of things that come in the way of a relationship, so it could be pain, it could be difficulties with sexual function, it could be other things and so when we assess someone or when we assess someone and their partner, we will sometimes refer them on for psychosexual counselling or to an organization like *Relate*, because there may be bigger issues. It may not just be about maintaining sexual intimacy in the context of pain.

Evans: That was psychologist Dr Sarah Edwards and before her, physiotherapist Katrine Peterson of the Pain Management Centre, University College London Hospital.

Well, the charity, *Relate* referred to there, provide relationship support for people of all ages, backgrounds and sexual orientations, to individuals, couples and families, with any aspect of their relationship that's not working for them. Denise Knowles is a counsellor, family counsellor and psychosexual therapist working with *Relate*.

Denise Knowles: Psychosexual therapy works with people who are experiencing sexual dysfunctions or sexual pain or any kind of problems in their sexual relationship. We work with them to work out what it is that's actually causing them the pain, what's causing the blocks to them enjoying themselves.

Evans: By pain, you're talking about mental pain?

Knowles: Mental and sometimes physical, because sometimes in sexual relationships, if people have got other conditions, they're living with other problems [and] *that* can cause them pain, so they might not be able to enjoy themselves sexually as they once did. That in itself can actually cause a sense of loss, a little bit of grief, a little bit of angst for the partner who perhaps is *not* living with any painful conditions. So they will come along just to have a chat about how that's affecting them psychologically and emotionally, and to find a way forward, so that they can both get what they want.

Evans: Do people with chronic pain come to you for help with getting through their relationships?

Knowles: People will come with all sorts of trigger points and chronic pain can certainly be one of those trigger points. But I think it's also important to say that some people will come along because they're experiencing pain that may *well* have been brought about through the difficulties that they've already begun to experience in their relationship, so we have to work out what comes first really.

Stress can create all sorts of chronic pain in our bodies, as can anxiety, and so can depression, so we have to work out what it is. Obviously, when someone is diagnosed with chronic pain, the impact on the couple-relationship and indeed the family-relationship can be immense and often needs to be talked through.

Evans: What are the tensions?

Knowles: One of the tensions can be, someone is living with a chronic condition that's causing them a great deal of pain, but won't do anything about it. They won't help themselves to help their relationship. The 'non-pain' person will actually say "Am I not important enough?", "For goodness sake, why can't you do something about that?", or "You're not the person I married" and "Why aren't we doing this and why aren't we doing that?". So they can start to have quite a lot of frustration and perhaps some resentments, which can lead to arguments and once they start arguing then they can often start blaming and that blame can be very toxic in relationships.

Evans: Now let me go back a little bit, how important is sex to a relationship?

Knowles: That's a really good question [laughs]. For some, it's not important at all, for others, it's *uber*-important. Then you've got a whole raft of people in the middle - yes sometimes it's important and sometimes it's not. But I think it's one of those things in relationships that, whilst it's happening, it doesn't matter about the frequency, but it's happening, it's ok. When it *stops* happening or it becomes less frequent and satisfying for one or the other, then that's when it becomes a problem. That's obviously when people might come along to *Relate* to explore what that is all about, so it can be important, very and not at all.

Evans: Explain how you work with a couple.

Knowles: Each couple can be... well, they are unique, there's no two ways about it. One of the things that is really good about therapy is that we haven't got a one-size-fits-all kind of answer to their difficulties. Nor do we have magic wands or crystal balls and I think that's important to say too.

What we will do, particularly in sex therapy, is take an extended assessment. We'll talk to them individually and that might actually uncover all sorts of really deep-seated beliefs about therapy and also about sex, [e.g.] their attitude towards sex, how they've learnt about it, where they've learnt about it, what indeed they've learned about it, can all influence how they are in their couple-relationship.

Once we've got all that sort of information, then we can actually look and say "Well, maybe we need to talk a little bit about this and bring you closer together in your attitudes, rather than actually having you poles apart". Then what we can do, if it's appropriate, we can actually then start to give them some kind of behavioural programme to go away and do at home, in the comfort of their own home, and then come back and tell us how they've got on with that.

We'll tweak that programme from there on in, but it's very much client led. It's not about the counsellor or the therapist saying "You must do this" and "You must do that" and "What? What's the problem with that?" there's no judgment and it's all very confidential.

I think that's what helps people to feel *safe* about actually approaching such organizations as *Relate*.

Evans: What do you mean by a behavioural programme?

Knowles: If you can imagine, particularly in sex therapy, there will be certain behaviours, this is why we do such an in-depth assessment. If we come across something that may be a cultural or a religious aspect to their behaviours, we have to actually unpick that, particularly in cross cultural /cross religion type relationships, so we've got to be very sensitive to each of those things.

But if you can imagine a couple that might have drifted apart because they're arguing, or maybe there's pain and there's this business of not managing it very well, they've stopped touching one another, they may have even stopped *cuddling* one another.

I've worked with people that even having a cuddle can be painful, so actually how do you help them to reconnect at a physical level? One of the things that we will do is ask them to put some time aside, perhaps to spend with one another and it depends where their start point is, as to where we take them or where we help them, guide them to actually try different touch, different strokes, different sensations, take sex out of the picture for a wee while, because that can put an *enormous* pressure on people, but actually just to help them to reconnect, often by just making the time to spend together.

Evans: This brings me a little bit to some of the myths that surround sex, you know, it has to be twice a week, it has to be spontaneous...

Knowles: Oh gosh, that word, spontaneous [laughs]. One of the things that I will often say is, "Spontaneity needs to be planned" and that takes me back to this idea of having time together, because if you haven't got the time together, then you can't have sex and if you're

always in a rush, you know, we can't even have ten minutes of lying down together, because I've got to get up and do this and I've got that to do and all the rest of it. Of course, that might be a bit of an avoidance and we'd have to understand what that's about, but actually, we have to have the time.

Once you've got the time put to one side, what you do with it can be quite spontaneous, but you can't start being spontaneous if you haven't got the time. With the busy lives that we're leading nowadays, we have to programme or diary in that time.

Once that's happened, once couples have got time together, it's important that they learn different ways to be with each other. Now, the way our brains are constructed, it's a wonderful piece of plastic in here and the plasticity of our brain means that we can learn different things and we're never too old to learn. So if we get people to repeat things, if we get our clients to actually repeat certain things, then, actually new neural pathways can be laid down, but there has to be a willingness and a determination commitment to doing that. So we will get them to practice different touches, different sensations, even relaxing... people are not taking the time to relax nowadays and so asking somebody to linger a little bit longer in the bath or the shower, they'll be going "I've got this to do or that to do...". It's really essential that they learn about their own bodies and how to relax and *that way* they can then start to share those experiences with their partners.

Evans: That's Denise Knowles, psychosexual therapist with the charity *Relate*.
Physiotherapist Katrine Peterson again.

Petersen: One of the key things that we need patients to get their head around is how *safe* is it for me to have sexual activity? There's no point in building up towards something that patients don't feel safe, so we talk a lot about [the] chronic pain mechanism, why something can be painful even though it's not causing harm. That, of course, can have a massive impact on the partner, they can be terrified of hurting their nearest and dearest. So sometimes, we invite the partner in just to hear that talk, and get their head around actually, yes, it can be painful, but it doesn't mean I'm causing any harm and there are strategies to cope with that afterwards.

Evans: In your group sessions, do men and women think differently?

Petersen: By and large, no, which is to some extent a surprise because we're bombarded with myths about how men and women think differently. But when you're sat with groups, it's exactly the same issues that come up and the same strategies that people need. There's just an anatomical difference, of course...

Edwards: ...and the same worries about what will happen if they can't have sex regularly, those are very similar for men or women aren't they?

Evans: Now, the other thing I'd like to talk about is age groups. Do different age groups react differently?

Edwards: I don't think so. What do you think?

Petersen: You can tell that's a bit of a hard question, we're having to think about it...

Edwards: I mean the only difference there *tends* to be is that our younger patients tend not to be in long-term relationships as much, so they're more likely to be worried about "Well if I meet someone new, what am I going to say to them? How am I going to deal with it?" Our older patients are more likely to be an established relationship, but they may be single as well. I don't think there's much difference.

Petersen: I don't think there's much difference. I'm thinking that maybe if a 20 year old says to me "In my relationship, sex is not important, because I've got pain and that's not an issue", I would *potentially*, and this makes me sound a bit prejudiced, but I may push it a little bit more.

Then if someone, in the context of their partner being there, or their husband being there, and they've come to a part in their life where they've decided that actually, penetrative intercourse isn't important anymore, not because of my pain, but that's just what we decided. I might be less inclined to push it, because that's the decision that some people make for all sorts of health issues.

Edwards: We see patients who've been married for thirty years and it's still something that they want to get back to, if it's been on the backburner for the last few years because of pain, just as much as a twenty-something might want to get back to that area of their life as well, so I don't think there's much difference.

Evans: Well, sitting in on our conversation is Meda Minard.

Minard: Yes I'm a gynaecologist from Denmark visiting this clinic.

Evans: You were just commenting that you think there is an age group difference between the attitudes of young people and old people...

Minard: I had a group session, just once, with older women and younger women having pain during sex. The older women are more open and already in this half hour conversation

in groups of six, they share their knowledge quite openly and often the young women below 25, I think, are much more shy, that's very new to me.

Evans: It's very interesting because we sort of assume, in our permissive society, that sex is common currency in schools and in universities and whatever. You seem to think that it's, or from your experience, if it is more common, they're keeping quiet about it?

Minard: Yes and I don't think they learn so much about sex just being a normal, natural thing. They learn about chlamydia and HIV and condoms and not how it's a challenge to have sex, it's not so easy. The older women know that, that it's not so easy, so they're more relaxed, maybe.

Edwards: Yeah, I think that, in a way, for the younger generation, there are even more myths about how sex should be and how people should be beautiful and always look good and always have an amazing time. I think maybe when you're younger, you maybe buy into those myths a bit more, as you're saying. As you get older, then reality bites a bit more.

Evans: Working with young people and possibly more mature people in the same group, does the influence of the mature person rub off onto the younger person, do they open up?

Minard: I think that if there's one person opening up in the group and giving her advice to the others, if she has something to share, it's even better than if I, as a health professional, give them any advice. It's much better if one of the other women tell the youngest, this is my experience, try this...

Edwards: Definitely, yes. One of the best ways of debunking those myths is for people to have an open discussion between themselves because then, they can really see that sex is not always spontaneous, that people do plan it, that it's not always amazing, that sometimes people don't enjoy themselves as much as they'd like to. As Meda said, in a way that's much easier to hear than if it's a professional talking *at* you, so those group discussions can be really helpful.

Evans: That's Dr. Sarah Edwards of the Pain Management Centre University College London Hospitals.

Psychosexual therapist, Denise Knowles, of *Relate* again.

Knowles: One of the things that it's important to make clear here, is that there is a difference between sex and intimacy. But when we start talking about sex, many people are just talking about penetrative intercourse. When we start talking about intimacy, we're talking about all the luxurious touching and stroking and cuddling and togetherness and the kissing

and all of those wonderful things that can take part. Sadly, if people withdraw from *that* because they're fearful they're not going to be able to follow through with the sexual intercourse, then the whole relationship becomes a little bit like a desert and it's devoid of any of that wonderful closeness and intimacy and that in itself creates problems. So the need is more for intimacy, perhaps, than it is for sex, as we get older and as our conditions change.

Evans: There's nothing actually quite like a cuddle...

Knowles: Oh it's wonderful, it's *almost* a cure for anything and everything. But of course, there are people that are touch averse and again if someone is experiencing a lot of pain, even someone touching gently their skin could set off all sorts of pain messages to the brain. It's very difficult then to cuddle. I might be the one that needs the cuddle and I might come up and want to give you cuddle and actually you can't tolerate that, so you will flinch and I'll go "Ohhhhh..." and so the distance immediately starts to grow through a lack of communication and understanding.

Petersen: Because of all the myths partly, people think "I can't really be intimate with my partner unless we go all the way and have penetrative intercourse" so therefore I may completely withdraw.

A lot of patients tell us that they completely withdraw, they don't like their partner touching them, and they're worried about kissing in case it leads something that might be painful. So even restoring the ability to have someone to hug you or kiss you could be the first step, just to draw out the intimacy that probably was there at one point, without having to focus on the ultimate act of having sex.

Desensitization is based on the ability of the nervous system to adapt, it's a neural plasticity that you may suffer with sensitivity to touch but it doesn't have to stay like that. If that's also driven by a large amount of anxiety and stress about what this might lead to, then it can be really helpful to have this communication tool whereby you say "we're just going to do things in a step-by-step manner". The first step may just be to work on tolerating touch.

Evans: In your leaflet, you give the image of walking on pebbles with no shoes on for the first-time. The first time, it'll be very painful and then you get used to it. When was reading that, I was thinking of my electric toothbrush and the first time you start using it, it's unbearably ticklish, but all of a sudden, it's gone. That's what you're talking about, the plasticity of the brain?

Petersen: Absolutely, just that initial new stimuli that you might not be used to and you would expect your nervous system to kind of kick up a bit of a fuss, going “Whoa, whoa, whoa... what’s going on here? Why are you kind of shaking your teeth? Why are you walking on some pebbles that seem unusual, because you’re not wearing shoes?”. So you would expect your nervous system kick up a fuss and if you already have a chronic pain condition, that could be quite unpleasant. But having confidence, which is something that we obviously support patients with, but hopefully also our leaflet will bring the image to mind that actually, in their quest to get to the water because it’s so enjoyable to swim, they will get through that. The more they do it, the more the body will get used to it and eventually the whole nervous system will accept this isn’t actually harmful.

Evans: The ink is still wet on *Pain Concern’s* updated leaflet on ‘Sex and Chronic Pain’ by Katrine Peterson and Sarah Edwards. You can read it or download it from *Pain Concern’s* website at www.painconcern.org.uk. Just go to the ‘Get Informed’ dropdown tab and you’ll find it with our other leaflets. The leaflet recommends the charity, *Relate* for all kinds of resources and support on relationship issues, including sexual relationship difficulties. And *Relate’s* website is <https://www.relate.org.uk>

Of course, I have to remind you 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. And don’t forget that you can download all editions and transcripts of **Airing Pain** from *Pain Concern’s* website. Once again it’s www.painconcern.org.uk.

I’ll end this edition of **Airing Pain** with advice from *Relate’s* psychosexual therapist Denise Knowles for couples, one of whom has chronic pain, but both partners are aware that something in their relationship is missing.

Knowles: If I have a couple where they’re *both* aware that something’s missing, actually we’re halfway to getting some kind of result and solution. The problem comes when *one* person recognizes something’s missing and the other person doesn’t.

But someone living with chronic pain actually has got an awful lot going on for them. They’re having to manage a whole range of different emotions and if they’re not able to share those, they’re so kind of distant, they’re not going to notice something’s missing because they’re so wrapped up in their own world. That can be a bit difficult because the person that *feels*

something is missing wants to say it and bring it to the attention of the relationship without pointing any fingers of blame, without actually saying “If only you would this or you would that...” and without actually hurting the other person.

Couples usually set up what I've come to refer to as a mutual protection racket - I won't say anything to him or her because I know it'll upset them, so it remains unsaid. In the counselling room all of that has nowhere to go, it's got to be talked to otherwise, why are you here talking to me as a therapist?

We can gently, gently understand the fears that often the person with the chronic pain is living with, with the disbelief that this is happening to *them* and putting together their new place, their new status if you like and integrating that into the relationship. Often the person living without the pain has no idea about the fears and the angers and the upsets and the lack of trust, the doubt that the person living with pain is now managing within them, because no-one's said anything, so that's what we will do - bring it out into the open, gently, sensitively and without any judgment.

Contributors

- Denise Knowles, Counsellor, Family Counsellor and Psychosexual Therapist with charity Relate
- Dr Sarah Edwards, Psychologist, Specialist in Abdominal Pelvic Pain at Pain Management Centre, UCL Hospitals NHS Foundation Trust
- Katrine Pietersen, Specialist Physiotherapist in Pain Management, Chronic Abdomino-Pelvic Pain at Pain Management Centre, UCL Hospitals NHS Foundation Trust
- Meda Minard, Gynecologist from Denmark

Additional Information

Pain Management Centre at NHNN, NHS University College London Hospitals:

<https://www.uclh.nhs.uk/OurServices/ServiceA-Z/Neuro/PMC/Pages/Home.aspx>

Relate, relationship support charity: <https://www.relate.org.uk/about-us>

Brook, charity for sexual health and wellbeing for under 25s: <https://www.brook.org.uk/>

FPA, sexual health charity: <https://www.fpa.org.uk/what-we-do>

Vulval Pain Society: <http://www.vulvalpainsociety.org/vps/>

Pain Concern website, leaflet on sex and chronic pain: <http://painconcern.org.uk/sex-chronic-pain-leaflet/>

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