

Airing Pain 110: Living with Cancer Pain

Living with a diagnosis, what palliative care entails, and non-pharmacological treatments.

This programme is funded by the Agnes Hunter Trust.

*According to Cancer Research UK, 50% of all people in England and Wales diagnosed with cancer survive their disease for ten years or more. This edition of **Airing Pain** looks at what pain management entails for the other 50%; those that live with terminal cancer.*

Kate Grafton, Lecturer and Professional Lead for Physiotherapy at Leeds Beckett University, speaks to Paul about her breast cancer diagnosis, her experiences with different treatments, the psychology of mindfulness, and finding the right support group.

Paul then heads to St Gemma's teaching hospice at the University of Leeds to speak to Professor of Palliative Medicine Mike Bennett who explains what palliative care entails as well as the importance of balancing treatment and quality of life.

Back at Leeds Beckett we hear from the Director of the Centre for Pain Research Mark Johnson, who has a particular interest in non-pharmacological treatments like TENS machines, acupuncture, and laser therapy. Professor Johnson talks Paul about the mechanisms of these treatments and their various limitations and strengths.

Paul Evans: This is **Airing Pain**, the programme brought to you by Pain Concern, the UK Charity providing information and support for those of us living with pain and for healthcare professionals. I'm Paul Evans and this edition of **Airing Pain** has been supported by the Agnes Hunter Trust.

Mike Bennet: A carer or family member who is really supportive and understands what they are doing can really help that person, conversely, a carer or family member who has very negative views about analgesia or, you know, shouldn't be taking drugs, you should manage or you should be more stoic and carry on without drugs, that can sometimes have a destructive effect or can inhibit the patient from achieving better pain control.

Evans: In a previous edition of **Airing Pain**, that's 101 (to listen to this programme click [here](#)) which like all editions is available for download from Pain Concern's website, we looked at issues around preventing and managing chronic pain in cancer survivors and, according to cancer research UK in England and Wales, that's 50% who will survive for ten or more years. Of course, that is a broad - brush statistic based on averages. There are many forms of cancer, each with its own set of figures. In this edition of **Airing Pain**, I want

to focus on the other 50%, those who have terminal cancer. Kate Grafton is a physiotherapist, she teaches at Leeds Beckett University and she has secondary breast cancer.

Kate Grafton: I don't like the word terminal, I don't see myself as terminal, but basically, it's cancer that is not going to go away, and I have been living with that for the past seven years. It's breast cancer, I have metastases in my bones, my liver, my lungs and my brain. So, the full house as we call it in cancer land. And I've had a lot of treatment, I've had just about every treatment that you could possibly have for cancer, and I do like patient experience talks, and talk about what the experience is like of living with an incurable disease, but actually being quite well, and how people perceive a cancer patient to be because I've got my hair, I look quite well, but I'm on my 104th cycle of chemotherapy, which is *amazing*, but equally terrifying, you know, in terms of how you manage that, and how you manage the side effects. So, we talk a lot about their perceptions of what a cancer patient is and what a palliative cancer patient is, because I am essentially a palliative, and there is no getting away from that and then seeing me and not knowing that I am in that classification really. I access the hospice, I am under the palliative care team and there is a lot of people out there like me, just like me, and we're going around doing normal stuff, and everyday stuff. And they need to be able to kind of put that into their clinical context around someone who wants to exercise, and wants to be well, and wants to be fit and eat healthily to their perception of someone who is in a hospice, very sick, end of life maybe.

Evans: We will hear more of Kate's story later. But that word *palliative* is one that confuses some people. Mike Bennett is the St Gemma's Professor of Palliative Medicine at the University of Leeds. St Gemma's Hospice, where he works, was the first hospice in the UK to be awarded the status of University Teaching Hospice in recognition of its research teaching and putting evidence into practice.

Bennett: Palliative care is generally the care of people with advanced progressive diseases, so in other words it's about people who are approaching death, with life limiting disease. And it's really supporting those people and their families around them in managing that process and of course that process can throw up physical problems, like pain, sickness, breathlessness, of course, and a host of other problems. But, also psychological worries, depression, carers often need support, there are other sorts of social issues about planning for bereavement, or planning in advance where that person wants to die, and having quite difficult conversations sometimes. But nevertheless, all those things by talking about and planning ahead, and resolving as many problems, we can hope to enhance the quality of care of people in that process. We can't extend life but neither do we hasten death, it is all

about improving quality of remaining life. For all cancers, pain is probably the number one concern people have when approaching the end of life, particularly with cancer. We know that about half of all people will experience some sort of pain, sometimes up to two-thirds of people will experience some sort of pain and probably about half of those patients it will be of moderate to severe intensity at times. So, it's a significant problem. We also know, unfortunately, that despite the availability of drugs and access to services, that at least a third of people will be undertreated for their cancer pain. In other words, they are not receiving the sort of optimum medicines, care and approach that would at least control their pain a lot better. Even in a country like the UK there is still undertreatment and we can do better, I think.

Evans: So, people say with, you mentioned prostate cancer, who can live for years and years and years with that, you're talking about long-term chronic pain.

Bennett: That's right yeah,

Evans: Or pain that may develop into long-term pain

Bennett: And that itself opens up a different issue which is traditionally an approach to cancer pain has been based on the World Health Organisation's analgesic ladder, this sort of step-wise approach of increasing strength of analgesia and, back in the 1970s and 80s when that concept was developed, virtually all cancers led to death within a few months and it was appropriate to that sort of point, but increasingly when some people are living for years with bone disease or liver disease, from their secondary spread of their cancers, the idea that long-term strong opioid treatment is correct for that group of people has been questioned now, so opioids are safe and appropriate medicines for relatively short-term periods, for weeks and months, but maybe not so for people who are facing many years of chronic pain; and certainly outside of the cancer context the idea of long-term treatment with strong opioids, I think that the medical profession is moving away from that really. I think because of the long-term effects of opioids on immune system and hormone imbalances, but also the growing research suggests that long-term, over many years, opioid treatment may not be associated with improvements in quality of life, and actually it is probably safer to be without them I think.

There's always a trade-off between whether a patient would want as much treatment as to relieve the pain completely, and will trade side effects, like drowsiness or put up with lots of burdens of treatment in order to be rid of the pain, whereas at the other extreme some people don't want anything that's going to make them any sense of drowsiness or tiredness, or affect their activities of daily living, and they will put up with more pain in order to avoid burdens of treatment or side effects of treatment. Most people of course sit somewhere in

the middle, and it varies as well as there are some days people want to sit on the settee and just be a bit more tired, to be relieved of their pain, other days people want to be more active and so will take fewer medicines or lower dose in order to put up with more pain, in order to be more active and get to the shops or see their grandchildren for example.

Evans: It's that balance of whether the treatment is worse than the condition.

Bennett: Yeah.

Evans: And how you make those decisions is very important.

Bennett: Exactly, and I think some of that is about understanding what's important for the person, in terms of what are their goals, what are their expectations as well, so setting expectations firstly about control of pain before relief of pain. We all want relief of pain, but actually trying to bring better control of the pain is the first sort of step, and so setting expectations around that initially and actually thinking well what might better control look like, and if that allows a person to move around their house a bit more easily or even just sleep more comfortably at night, breaking down those goals into small steps is a way of ensuring that you might realise those goals more quickly as opposed to saying, well let's relieve pain completely forever, that's very unlikely to happen in many situations.

Grafton: I haven't had that many symptoms from my actual cancer. I wouldn't have known on diagnosis that I had cancer everywhere, I was diagnosed secondary from the start. So, in terms of symptoms like brain mets: no symptoms at all, the classic headaches and blurred vision and all of that, and I've actually had brain mets from the start, so I've lived with that for seven years now, but they're the least of my worries.

Evans: Now, some people say that the cure is worse than the disease. Does that ring a bell?

Grafton: It does, and some of the treatments have been more, what word do I want to use, challenging, let's go with challenging shall we, than others. Chemotherapy for me has pretty much been oral chemotherapy. People perceive it as an easier chemotherapy, because you're not having to sit and have intravenous drugs, and you don't get as much nausea and as much diarrhoea, you get some, but it's actually a longer term, so they put you on that to try and keep you weller for longer really. The brain radiotherapy was horrific, really horrific and affected me, personality wise for quite a long time afterwards, I became very sweary and quite aggressive, and team meetings were really fun actually [laugh], it was quite fun wasn't it, Mark [laugh]? And that wasn't the kind of person who I am, that was very noticeable to other people around me. Physically, not many affects at all, but psychologically and personality wise that was really challenging to go through that. The bone mets were very

painful, my spine actually fractured, pathological fracture, and I ended up having spinal fixation, and that's left me with neuropathy. They're not awful, they are just irritating, I think I would say, irritating.

Evans: That's news, you have cancer, or your husband, your wife has cancer, must be up there with about the worst pieces of news you can have. Psychologically, that drags people down as well before they can make a decision about the pain.

Bennett: A diagnosis of cancer is clearly a bad news conversation, and there are cancers that can be cured or put into remission, but that's something that you won't know until time passes really, at that moment when you've been diagnosed I think the world crashes in at that point I think, so trying to cope with that existential threat, that you might die, is a significant blow, because what we are asking people after that is to feel in charge or in control of their symptoms, and actually that is a probably a situation where it is very difficult to obtain that when you are feeling that my very existence is threatened

Evans: How would you help people regain control of their decisions of their lives?

Bennett: I mean all these things are in parallel, I think, but providing important information, so actually what does this mean, what's maybe the prognosis, what might treatments offer, what are the likely chances of improvement, so just trying to help people orientate with a bit more information. I think alongside that trying to understand their fears and concerns, talking that through, sometimes those fears are very rational and appropriate, sometimes they're irrational in the sense that they are very unlikely to happen or it's an exaggerated fear based on what we think is from a professionals perspective about how the disease is likely to unfold, alongside that helping people maintain their daily activity, helping people to socialise, keep moving if they are struggling to get out of bed, it's about normalising things as much as possible, I suppose, and helping people function or get back into gear for a period of time.

Evans: And the personal counsellor of the family, the spouse, the sons, the parents, they can be an important part of the team.

Bennett: One of the philosophies of palliative care and healthcare in general I think should be that it's very difficult to isolate a person outside of their social network, their family support, so we see people as parts of teams and units, and it's the family unit that we are trying to support. We know from lots of research including in pain itself, that carers or family members, a close spouse or sibling's attitude towards pain or analgesia can have more influence on pain outcomes than the patient's own attitudes and knowledge about analgesia, so carers are very influential for good or for bad in the sense that a carer or family member who is really supportive, understands what they are doing can really help that person.

Conversely, a carer or family member who has very negative views about analgesia or, you know, shouldn't be taking drugs, you should manage or you know you should be more stoic and carry on without drugs, that can have sometimes a destructive affect or can inhibit the patient from achieving better pain control, so trying to tackle the family unit if you like is probably a better strategy rather than just focusing on the patient alone sometimes.

Evans: You look like a very settled person.

Grafton: [laugh] Yeah [laugh].

Evans: What techniques do you use to manage it?

Grafton: What do I use? I really like Kubler-Ross, do you know who I mean by Kubler-Ross? She's a psychologist that talked about the different stages of the grieving process, but not necessarily towards someone passing away, grieving in a bigger context, and she talks about stages around anger, and I swing very much from denial [laugh], I live in denial a lot, to acceptance, and certainly this year I have had to have a lot of surgery and a lot of time off, and I know I have gone through all of those five stages. I do quite a lot of meditation, I do mindfulness, I try and eat as healthily as I can but I don't really buy into all of the superfood things, I'm not a kale kind of girl, that's not going to be me. I exercise, and I think as a physio background I think I would naturally probably do that anyway. I get a lot of support from online support groups and from places like Breast Cancer Care, and Breast Cancer Now, they run really good support groups, and I try really hard not to let the cancer become part of my life. It *is* my life, it's me isn't it, it's part of me, but I changed my thinking on it a long time ago. Instead of trying to battle it and fight it, and all of those kinds of terminology, they don't work with me, I would say I am more of a pacifist, so when I visualise my cancer, most people visualise in the chemotherapy going in and kickboxing and beating the cancer up. When I visualise it, my cancer is truffles, and the chemotherapy is like little pigs going round snuffling out the truffles, and I don't know why that came but that's what happened when you do the visualisation techniques. I like kind of sitting there when I meditating I think about the chemotherapy going in and getting rid of it in a peaceful way, I don't like the terminology around fighting and all of that, it doesn't wash with me because you can't fight your own genetics, you can't fight your own immune system and by that nature, when you die you've lost a fight you can never have won; and that kind of upsets me when people talk about that because you don't fight it, there is no fighting, you just have to be at peace with it really. Does that make sense?

Evans: It does make sense, but you are using techniques that may be good for people with any long-term condition.

Grafton: I'm very lucky in the fact that I am a health professional and I know where to access these, and I read, and I educate myself on what can help. I'm quite aware of the lure of a cure is great, but there is a lot of charlatans out there. And there is a lot of vulnerable people out there that don't know where to go for help, and sit there for a long time, sad state really, and there is so much out there that can help and you have to be open-minded with this because there is no definitive 'this is what you will do to make you feel better about this'. And not everything has worked, I tried something called the Emotional Freedom Technique where you do tapping and things, not for me, not for me at all, I don't really like Reiki and massage. The in thing at the moment is infra-red therapy, well sitting in a sauna to me is 'errr', sweating in front of a load of people is not for me, but I think you have to find what works for you, and just because there is no evidence for it, doesn't mean to say it's not going to help you.

Evans: Kate Grafton, now of course what scientific scrutiny or evidence does give is the confidence for us to know whether a device does what's claimed on the packet, and most importantly whether it's safe. Mark Johnson is Professor of Pain and Analgesia at Leeds Beckett University where he's director of the Centre for Pain Research.

Mark Johnson: I'm particularly interested in non-pharmacological treatments, treatments that we call electro-physical agents so things like transcutaneous electrical nerve stimulation or TENS for short, acupuncture, kinesiomyology taping, low-level laser therapy, and more recently we're interested in visual feedback techniques, mirror-box therapy and virtual reality.

Evans: You brought up the TENS machine, a TENS machine is something that many people with chronic pain may have experience of. I use a TENS machine and it does very little for me, I know other people who have wonderful affects from it.

Johnson: I have been researching into the fact there's influence and response to TENS for most of my career. I originally did my PhD on it. What TENS is, is a battery-operated device that generates electrical currents, that are then passed across the surface of the skin using adhesive electrode pads that you attach onto the surface. The currents are mild and they shouldn't cause pain, and the purpose of the currents is to activate the nerves in the skin and the underlying tissue. The nerve that you are trying to activate when you are using TENS are the same nerves that you activate when you rub pain away. So, we often say that TENS is used to electrically rub pain away. And the idea is that when you're stimulating those nerves, you get a sensation of tingling and sort of pleasant pins and needles sensation associated with the currents activating the nerves. And that sensation, hopefully, overrides the pain that you're experiencing, or perhaps distracts you from it. Or it might actually completely alleviate it so that you no longer feel the pain at all.

Evans: I happened to have brought my own TENS machine with me. It's about the size of a small transistor radio, very, very few controls on it. I plug little parts in and I get a sensation, which like little pinpricks across my hand or wherever I put it. What I would really love to know is do I have to feel it? Is it no pain, no gain?

Johnson: Certainly not no pain, no gain. So, one of the things we say about TENS is when you pass the currents through the skin, you should not feel a painful sensation from the currents themselves, that's really important. If you are, you've turned the TENS device up too high. And we've done experiments in the laboratory with healthy human individuals using experimental pain. We've also looked at clinical research that's been conducted. For example, we did a large systematic review, which summarised all of the findings of clinical trials. And what we did in that systematic review was compared TENS, when the participants of the trials could definitely feel the tingling sensation, versus the results of those trials where patients could not feel the tingling sensation. And what we found was, if you didn't feel the tingling sensation, then TENS was less likely to alleviate in this instance, post-operative pain. Similar findings have been shown in systematic reviews for chronic musculoskeletal pain as well.

Evans: I've got two pads across my shoulders now. And what I'm feeling is just gentle pulses going across – actually, it's quite relaxing. When I turn it up, it feels more of a, you know, well, I can feel it, put it like that.

Johnson: Yeah. It's nice to see you're smiling when you've got it on as well. And I think that's important because, with interventions like TENS, it's important that the sensations you experience are pleasant. The body likes to have sensations that are comforting to it, especially when you're experiencing something like chronic pain, or acute pain for that matter. So more comforting the sensation, the more likely it's going to be of benefit to you. And that's why we use, for example, warmth therapy, where you might put a hot water bottle onto an aching back, for example, because the body wants to feel safe, it doesn't want to feel threatened. And when a body's really experiencing pain on its own, the body feels threatened. So, if you can add additional sensations that make the body feel more comforting, then it's going to feel less threatened. And of course, the key thing about that is when your body's feeling less threatened, you're more likely to move and we know that movement is medicine. Motion is lotion as the physiotherapists often say, and movement is tightly coupled to pain. So, we like using TENS for conditions where patients might feel frightened to move because when they move, it's painful. Well, if you put TENS on to that body site, you feel the TENS sensation so that when you start to move the pain is in the background, which then reduces that fear of movement and that avoidance of movement.

Evans: So, what's going on this current now is going from one shoulder to the other. Is this diverting your attention away from the pain? Or is it physically doing something?

Johnson: It is physically doing something, we often say that TENS closes the pain gate, I don't know if you've heard of that term before. The term 'closing the pain gate' is really a metaphor to describe stopping information about tissue damage and harmful events that occur in our body, stopping that information from being transmitted from the site of, for example, tissue damage to the brain. So, it's preventing the onward transmission of those pain-related impulses. They're not actually transmitting pain though, because pain is a construct of the brain, we often say no brain, no pain. But there are nerve impulses that are being sent along pathways that are taking information from noxious events that might be happening in or on the body, and tissue damage that might have already occurred in the body. So, what TENS does, is it prevents that onward transmitting of noxious information by stimulating the touch nerves, and the touch nerves, when they send their information along a different pathway to the pain related information, when that information gets into the central nervous system, it prevents the onward transmission of the noxious information. So, less information gets to the brain about noxious events, which hopefully alleviates the person's pain.

Evans: Now one thing about people with chronic pain or anybody with a long-term illness, sometimes they get desperate to buy everything that's going, because nobody sells anything less than perfect cure. I brought a couple of electrical things along with me. One of them is, I'm not going to tell you what it is but you tried it for the first time earlier.

Johnson: So, this was a transcranial electrical stimulator. So, it generates electrical currents, they're slightly different in their properties than the currents that are generated by TENS. And the currents actually passed across the ear lobes. So, you have one electrode on each ear lobe. And when you turn the device on, you don't actually feel a tingling sensation in the same way as you feel a tingling sensation with TENS. But when I used the device, what did happen was I felt a bit of vertigo. So, the currents are being transmitted through the ear lobes, and then into the tissue around the ears, and potentially into the brain itself. Although I don't know whether that's actually reaching the brain, because I don't have a cathode-ray oscilloscope to detect where these currents are being delivered to. But it produced a vertigo type sensation for me. Now, I'm interested in and I've always been interested in these types of devices, I call them TENS-like devices, because they're passing currents across the intact surface of the skin. But they're not using the same types of currents as TENS. And they're not applied in the same way as TENS. And the challenge I think, for patients is trying to determine well, which of these other devices may be beneficial

for their particular condition? I'm quite sceptical, I have to be upfront about this, sceptical because there's not much evidence that's been produced on the clinical effectiveness of these devices. That's not to say that they may not help you or your pain. But we don't have sufficient research to make judgments about whether they're helping your pain. But I think secondly, I'm sceptical because one of the challenges I think, for patients and for practitioners for that matter, is trying to select which treatment is more likely to have a beneficial effect compared with other available treatments in your toolbox or available over the counter or the internet. And I think that's quite hard to make judgments on. I would always go for something where there is some evidence to support effect; where the device, perhaps, is relatively inexpensive; where there's definitely no harmful effects from the device; and where you can administer the device yourself, and it being relatively easy to use. Of course, traditional TENS fits into that category, but some of the other electrical devices on the market less so.

Evans: That's Mark Johnson, Professor of Pain and Analgesia and Director of the Centre for Pain Research at Leeds Beckett University. You can download all editions of *Airing Pain* from Pain Concern's website, which is painconcern.org.uk. There you'll also find further information about living with and managing cancer pain. Of course, backing up what Mark said there, 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, he or she is the only person who knows you and your circumstances, and therefore the appropriate action to take on your behalf. And if we, or Mark, still haven't convinced you on the importance of getting expert advice, here's Kate Grafton to finish this edition of *Airing Pain*.

Grafton: It's interesting the support groups, there's three or four of us on there that have come from a health professional background. And a lot of people come to us and say what do you think about this? And it's not for me to tell them what they should go away and do. But some things you have to say, actually, if you're getting that advice, is that person qualified? Have they got some knowledge of this? Or are they just trying to rip you off? And I always say, you know, go to a qualified dietitian for food advice. You know, speak to your oncologist, speak to your breast cancer nurse and get some proper advice. I love my oncologist, he's mad, he's completely, and he's on my wavelength totally. But he laughs at me when I say I'm doing this and I'll go you know, there's no evidence for that. You know, and I'll go, yeah, but it makes me feel better. And he's like, Well, okay, as long as it's doing no harm, you know, I'm not going to say no. And I will say to him, I'm not asking you for permission. I'm telling you I'm doing it [laugh]. And he looks at me as if to say [noise] [laugh]. But I would hope he would trust me enough to know me well enough now that I'm not going

to do something stupid, that's going to cause me any harm. I'm not going to sit and take, you know, black cohosh or some weird homoeopathy that's going to interact or do nothing to my chemotherapy because I'm educated and sensible enough but there are a lot of people out there that aren't educated and aren't aware of that.

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- Professor Kate Grafton, Principal Lecturer and Professional Lead for Physiotherapy, Leeds Beckett University
- Professor Mark Johnson, Professor of Pain and Analgesia and Director of the Centre for Pain Research, Leeds Beckett University.

More information:

- Cancer Research UK: cancerresearchuk.org/
- Macmillan Cancer Support: macmillan.org.uk/
- Shine Cancer Support: shinecancersupport.org/

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