

Airing Pain Programme 84: Cancer pain

How cancer survivors can manage long term pain and creating a home from home at the hospital.

*More people than ever before survive cancer, but the disease and treatment can have long-lasting effects on health, including chronic pain. In this edition of **Airing Pain** we visit Maggie's Centre, Edinburgh, which pioneers a compassionate, personalised approach to supporting those with cancer and survivors of the disease.*

Cancer Nurse Andy Anderson explains how the tranquil, homely environment at Maggie's gives service users a chance to regain control. Claire Tattersall speaks about her long struggle with bone cancer, the stigma surrounding the 'C word' and the pain resulting from her life-saving treatment.

While Claire takes her pain as a reminder that she's 'still here', the immense gratitude many survivors feel can lead to their pain going unreported, says cancer pain specialist Dr Lesley Colvin. She explains why cancer and its treatment can lead to chronic pain and how we can improve pain management in palliative care and for survivors.

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

It is good that we are curing more people of cancer but we have to recognise that not dying is not the same as being well. No one should face the often severe long term effects of cancer. That was the foreword to the charity Macmillan Cancer Support's 2013 report 'Throwing light on the consequences of cancer and its treatment'. In this edition of **Airing Pain** I'll be looking at one of those long term effects, that is chronic pain. Lesley Colvin is a consultant in Pain Medicine in the Lothian Pain Service. She's run a combined clinic with palliative care for the last 16 years. So how prevalent is long term pain following cancer treatment?

Lesley Colvin: I think it depends on the cancer treatment, so if you have had chemotherapy it depends on the type of chemotherapy you've had. So there are particular types of chemotherapy where your risk of having a long term neuropathy effect in your hands and

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your feet might be up to 50 per cent. Globally, if you look at all chemotherapies, in the published literature it's round about 30 to 33 per cent, who'll still have some form of neuropathic damage a year down the line. And then after cancer surgery it depends on the type of surgery, so after thoracotomy up to about 70 per cent of patients might have horrible pain afterwards. After a mastectomy round about 30 per cent. So it also depends on how hard you look for it. And I think that goes back to... it's really important to assess pain properly, but also to enable patients to ask for help when they need it.

Evans: Lesley Colvin. One source of help is provided in 20 hospital locations across the UK by the charity Maggie's. In Edinburgh it's in the grounds of the Western General Hospital where I met Andy Anderson. He's a cancer nurse working full time for Maggie's.

Andy Anderson: Maggie's is a support resource for anybody affected by any type of cancer at any stage. So, many people who come to the centre are people newly diagnosed with early stage bowel cancer, early stage breast cancer, looking to fully recover from their diagnosis, but understandably in the flux of upset and confusion and distress about their diagnosis. So a lot of the support we provide for those people is helping them through treatment and importantly helping them in their recovery back to whatever their new normality is.

But we also support a lot of people for whom their diagnosis means that they won't recover from their experience of cancer. And it's supporting them through that experience and supporting them to whatever it is that they wish to be supported to. Importantly also, the support is for family members as well, the children of, the siblings of, the partners, family members of somebody with a cancer diagnosis.

Evans: You used the word 'normality'. Just getting here, to describe it, it's a large general hospital in a residential area, quite an upmarket residential area I would think. But we've come through a fantastic scented garden. There is nothing hospital-ish, if that's such a word, about Maggie's Centre.

Anderson: That's exactly right, and that's a very deliberate process, you're right. This is a huge, overdeveloped hospital, with a massive general hospital but also a cancer centre bolted on to that. As most hospitals in the UK are, they've grown from a very small cottage hospital or general hospital and then major bolt ons. So it's a big hospital campus. But we're a very small domestic scale building on that big hospital campus, with a beautiful garden surrounding us, an environment that feels nothing like a hospital. When you walk into the



centre you walk straight into a kitchen, with a kitchen table, an opportunity to have a cup of tea or coffee, to sit and to meet other people in a similar situation. But also the space offers an opportunity to meet healthcare professionals and to talk through what that experience means for you, or for your family as well.

Maggie's aim was to try and personalise this building, to make sure that when you stepped in you came in as a human being, rather than a number and a name associated with a cancer diagnosis. And that's exactly what the building and the built space offers the centre.

One of the fundamental things that Maggie's offers is people a space to start to regain control, when they've felt very vulnerable, very overwhelmed, either because of a diagnosis or because of the complexity of the symptoms or side effects that come with that diagnosis.

Evans: Just go back to the beginning of what a person might feel when they get that diagnosis.

Anderson: So what people describe to us is often there's been a lead up to the diagnosis process itself, they've had some concerning symptom, they've been to their GP. So they have an awareness that something's not right.

But most people try really hard not to acknowledge that that could be the case, they're very fearful of acknowledging that reality. And when it's described to them often there's a massive state of shock, overwhelm, fear. Some of that fear is associated with historic reference points, so the fact that their mum, or their father, or their uncle died a difficult death associated with cancer and they *assume* that's going to be their own story.

Interestingly though, for some people there is a sense of relief because they've been wrestling with a difficult symptom, a difficult process for a while and at least now there's a name to it. And, importantly, there's a treatment plan, there's a strategy for dealing with my diagnosis. But most people definitely require some advice, some guidance, some translation and some support associated with that.

Evans: And going back once again to that word 'normality'. How does what you describe those feelings – and I'm sure there are many different feelings – how does that affect the world around them, their family, their colleagues, their siblings?

Anderson: What a lot of people describe as somebody with a diagnosis in the centre, is that their family members, their friends, their colleagues, their peers, their neighbours, are all



equally shocked, but sometimes feel even more out of control because they've got no vehicle to actually do anything tangible to make a difference. The individual with a diagnosis has a treatment plan and although they're going to have to deal with surgery, radiotherapy, chemotherapy, there's a structure. And that's their job, that's their job for the next six months. So they know they've got something tangible to do.

Often what they describe is that they're having to pick up the pieces of their husband, or their wife, or their children, or their neighbours, or their colleagues, because their colleagues' expression of upset and love and distress for them can often be overwhelming. So a lot of people talk about not only managing their own reaction and upset, but having to spend a lot of time managing other people's upset as well. So that is often described in this centre.

Claire Tattersall: My name is Claire Tattersall, I'm 39 and I'm at Maggie's Centre because just before I turned 21 I was diagnosed with a very rare form of bone cancer. I had a year and a bit of treatment, I've had 30 odd operations over the last 18 years, so Maggie's have supported me all the way through that.

Evans: Andy was just telling us about the emotional journey of having cancer, that first thing and the effect on the family, can you tell me how that affected you?

Tattersall: At the time I was playing semi-professional hockey, so when I was diagnosed, for months they had put it down to a sporting injury, so when the diagnosis came it was a complete shock. I thought I had my career in the ambulance service, a paramedic, my hockey career, which I would retire when I chose. And in one foul swoop that was all changed.

So the effect on my family was even worse, because I tended to joke my way through it, whereas they were the ones that were coming at home at night time and not knowing exactly what was going on, because obviously I was there and it was happening to me. So they only had my word to go on and the doctors' word to go on. And I suppose as parents, and for my brother, it's the last thing that you expect. It really affected our whole family greatly.

Anderson: A lot of family members come to the centre, so last year 40 per cent of the visitors to Maggie's were family members. And they're all coming to say, this is upsetting for me, but how can I be the best resource for my husband, my wife, my dad, my sibling, to help them through their experience? Partly so they can come here and name their upset without



then upsetting the person with the diagnosis, but also that they can come with more of a constructive approach to be the alongside person through that.

We try often to provide support separately, but quite often we're supporting families as a whole family as well. Yesterday I met eight members of a family who came together to think about how the mum could be best supported by the parents, the siblings and the children, and it was a really constructive conversation.

Evans: What did you tell them?

Anderson: So some of it is knowing that cancer is something that can be spoken about, being honest and being real, trying not to obscure your own emotional response, speaking about your emotional response and being honest as a family about that. So each person having a responsibility to account for their own needs, but also some of the family members stepping up to the mark a bit more.

So the mum in this situation was the rock of the family, but also the chief cook, the chief bottle washer, the chief cleaner upper. So some of the children's role was actually to step up to the mark and make sure they picked up their socks. Some of it also was parents knowing what would be valuable in terms of chauffer servicing, in terms of providing pre-cooked meals, but also being there as that resilient emotional support for the individual affected.

Evans: Did the cancer define you as a person?

Tattersall: Yeah it did. I can remember saying to a couple of doctors, 'I'm a person with cancer, I'm not cancer with a person attached'. And that happened out in the world as well, people would... 'there's Claire with cancer' – 'no, I'm just Claire'. I wasn't a walking tumour. I wasn't a ticking time bomb. In my head, I was still me.

But some people found it really difficult to dissociate the cancer and me, whereas I found it very easy, because I was so fit then I had not so much side effects as some people have. So I could, for the first six months at least, I could get on with my life, the two weeks that I was at home out of every three, pretty much as normal. I was still going and playing hockey, I was still working, I was still doing youth work. I never lost my identity, but I think other people struggled to realise who I was anymore.

Evans: People still don't like using the word 'cancer', it's the 'C word' or it's the word we don't talk about. I guess 18 years ago it would have been even more like that?

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Tattersall: It was. I remember on a Friday afternoon being told from a rheumatologist that I had a tumour. Now a 20-year-old, on my own, Friday afternoon in a clinic. I don't remember much about the drive home, but I do remember thinking, should I tell people? Because there was still a massive stigma to having had cancer, it was still classed as dirty and you know, you must have done something to cause the cancer. And that really played on my mind as to should I tell people.

And then, actually, if people can't deal with it, then that's something that they've got to work out, I just have to be me. Alright, the illness has had a massive impact on my life, in a way that I would never have wished on my worst enemy, but it's just a word. You know if you say it, you're not going to catch it. I know a few people who have had cancer and are scared to talk about it once they've got the all clear, in case it comes back. Well it doesn't work like that.

Evans: Do you have cancer now?

Tattersall: No, I don't. I have the all clear from the cancer. The only thing I have to live with is the after effects of all the treatment and the surgery that I had. Because the surgery was to save my life, so there wasn't any thought of what will happen down the line, so there was a lot of nerve damage done. So now I have to live with the pain and the constant surgeries, but no I don't have cancer. As much chance as anyone else now.

Evans: That's Claire Tattersall, speaking to me at Maggie's Centre in the grounds of the Western General Hospital in Edinburgh. Andy Anderson again.

Anderson: Sadly, we see a lot of people for whom their diagnosis, although it may have been fully surgically removed and fully treated with chemotherapy or radiotherapy, because of the area presented in it left them with ongoing nerve-related issues or nerve-related problems. Or because of the surgery itself – it's left them with ongoing complex pain issues.

Some of those can be very well managed, and some are much more complex and require high level skilled symptom control specialists to be able to be involved with. Often an oncologist is well equipped to be able to prescribe a range of analgesics, often GPs are very good at providing good analgesic support, but for the most part the population we support, who have more complex pain issues, require the specialist support of sub-specialist pain control teams, either within the hospital or within the community.

Evans: Pain consultant Lesley Colvin again:

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Colvin: I think the other issue – and I do see a lot of these both in the combined clinic and in the chronic pain clinic – is that cancer treatment itself, to do the job it has to do, is quite toxic, but there are side effects, and one of those side effects is pain. Chemotherapy, very effective chemotherapies, but depending on the chemotherapy you get, at least half of people may have ongoing neuropathic type pain.

Evans: So I just asked Claire the question, ‘do you have cancer?’ And she said ‘no’. And I said, ‘do you have pain?’ And she said ‘yes’. So what’s going on there?

Colvin: Obviously some patients are cured of their cancer, they go to the oncology follow up clinic for a number of years, they’re discharged at five years cured of their cancer, but what they may still have is ongoing pain, either as a result of what the cancer did to their body in the first place, or often due to the treatment. So either the chemotherapy or surgery is the other major one. So cancer surgery by definition is not minor surgery and there can be long term problems with that and one of those is pain.

Evans: I know every case is different, where do you start, how do you start to manage that?

Colvin: Every case is different – and I think that’s really important actually, you know, assessing patients individually and working out a management plan with the patient, so that they’re involved in it, I think is the basis for successful management. The other thing that is also very important, is when you see a patient and you make changes to try and improve their pain, is having some way that you can reassess the pain effectively, to reassess what has happened as the result of the things that you’ve changed.

And sometimes I think our healthcare system is set up with this huge pressure on us not to follow up with patients, and that can actually be quite challenging. And often, particularly patients with complex pain related to their cancer, you need to see them quite frequently to make sure that things are fine-tuned and that they’re as good as you can get them.

Evans: You have a beaming smile across your face, but you’re still in pain?

Tattersall: Yeah, as one of my consultants said the other week, I turn 40 in December and no one thought I was going to make it. I shouldn’t have really even turned 22. So pain, as much as it drives me insane and sometimes I’m climbing the walls, I’m still here. And pain kind of reminds me that I’m alive.

Evans: Claire said that 'the pain reminds her that she's alive'. Now, I find that an extraordinary glass half full statement.

Colvin: Yes, and I think that that's a very good point because often you feel humbled with some of the patients that you meet, who've been through cancer and have ended up with really quite dreadful problems actually, pain problems, that are long term, that are probably not going to go away. And it is one of the things that you think, 'gosh, I don't know if I would be like that in the same situation'. They are so uncomplaining. That's important, actually.

And, again, I think that – not willingness, but lack of saying 'what can you do for me?' – is a bit sad, actually, because often there's quite a lot we can do for people but it takes people maybe a long time to get there. Maybe that's part of the process, but maybe we could change things a little bit.

So, for instance, we talked about thoracotomy, and 70 per cent of patients will have pain a year down the line, actually, when you assess them at six weeks, when they're assessed by the surgeon six weeks afterwards, or by the oncological team, if they've got difficult pain at that point they will probably still have pain a year later. So maybe at that point, instead of waiting for them to complain, we should be saying, 'actually, let's get you to see a pain specialist, or a palliative care specialist with a particular interest in pain and symptom control'.

One of the things that has struck me about the difference between patients who've been through the cancer journey, to maybe a patient who's got chronic back pain, is that patients are so grateful that they've had this huge amount of input and that they're still alive, is that they will put up with an enormous amount of really unpleasant pain, before they ask for help. And I do see patients who, seven years down the line, they've ended up coming to the pain clinic and we've done something that's helped them, but they've put up with it for seven years.

So it's finding a way to enable patients to ask for help and maybe part of that is early on in the cancer journey. So, for instance, if they're coming to Maggie's Centre and someone in Maggie's Centre realises that they're sore, having them flag up that there's something that can be done about it, rather than just putting up with it.

Evans: And that's one of the advantages of a place like Maggie's Centre, a drop-in centre, if you like [**Colvin:** that's right], that they can talk to people who know what's going on and can



reassure them that that's just an ache and a pain, or, on the other hand, say, 'actually, I think you ought to just have a word with somebody about that'.

Colvin: Yeah, because one of the things that I do notice is that quite a lot of the oncological follow up is done by experienced clinical nurse specialists. And they're actually – I would say – sometimes better. Maybe they've got a little bit more time, maybe the patients talk to them a bit more, but they're maybe better than medical staff at directing patients towards the pain clinic, or the combined pain clinic with palliative care.

Anderson: Most people describe at the end of their treatment, whether it's with curative intent or whether it's with maintenance, that their radar is incredibly highly-tuned and every new ache, every new pain, every new cough, every new mole is cancer before it's anything else, in their emotional response. It takes a while for them to bring in their good, logical, calm, rational thinking.

And often their logical, calm, rational thinking is accelerated by being able to come back to the Centre, or by being able to check in with their nurse specialist in the hospital, the nurse specialist that was that fortnightly check in through the whole treatment. They could give the nurse a call and say, 'listen, this is going on for me today – is that something to be worried about?' And it can be talked through and a relief point given. That alarm bell process is very difficult and I think that lasts with people for a good two to three years after the completion of treatment.

A lot of the conversation is normalising, a lot of the conversation is giving people a different perspective on their experience and also helping them to bring in their good, rational, calm thinking. The fear that they have diminishes that logical thinking, but when they've sat with us for ten or fifteen minutes, then themselves they start to say, 'actually, you know what, on reflection I know that I'm able to do x, y and z to work my way through this, thanks for your guidance and thanks for your support'. So, often we've not given a definitive direction, it's the individual who's made that decision, but we've helped them get to that position of decision making.

Colvin: I think patients, when they have a diagnosis of cancer, there's obviously the shock of initial diagnosis, there's a whole complicated and often unpleasant journey of the cancer treatment and thereafter and throughout that, having somewhere where you can maybe step aside from the very clinical environment, have the support but also the expert understanding and expertise that exists in Maggie's Centre is enormously helpful for patients.



In oncology centres there's a huge pressure to manage patients who have active cancer, and often patients say that they get a huge amount of input during the time that their cancer is being treated and then chemotherapy finishes, what do they do next, where do they go for support? And Maggie's Centre actually fills a gap there. It's actually a really nice example of working between the NHS and charitable organisations, which I think provides an enormous amount of benefit for patients.

Evans: It must feel like an incredible relief to walk into something on hospital grounds that doesn't look like a hospital, there are no white walls, there are no people in white coats, it's like a cafe out there. That must be like a haven of peace.

Colvin: I think you're absolutely right and one of the things we know about pain is that stress and fear will make pain worse, not through imagining it, but just that is the way that pain works, so anything that can support patients to alleviate that will not only help their general quality of life, but actually potentially help manage their pain. Obviously, medication has a role in that, but there are side effects to medication, there's no side effects coming to Maggie's Centre.

Evans: Do you manage your pain not just by drugs, but with what we call talking therapies, the psychology, all done these days through pain management programmes?

Tattersall: Yup, I see a psychiatric nurse who does CBT (cognitive behavioural therapy), to try and work on relaxation methods and taking yourself out of that moment when your pain is really bad. If you can catch it before it gets really bad, then it can help, because if you distract your mind for long enough, then it's got to take it away from the pain. It's only when you concentrate on the pain that it takes over you.

And, obviously, some days the pain are so bad that those things don't work, but a lot of the time they do. And the mental health team, as part of the pain team, have been amazing, because I wouldn't like to be treating me, because I'm a bit stubborn [laughs], mental health I struggle with because I'm a fixer. Give me a physical challenge, like I'm in a wheelchair I hope to walk again, no problem, I will spend seven days a week at physio. Ask me to talk about what's going on in my head, then I struggle. Ask me to think about how I feel when the pain is really bad, I struggle. But I'm getting better, because people work with me and have patience.



Evans: Even though you say, 'I don't like the mental stuff', you obviously manage it very well. Do you use techniques? Visualisation...?

Tattersall: Yeah, visualisation and breathing exercises. Most of my pain is in my shoulder and my neck, so I try to visualise that these parts of my body that are causing me so much pain aren't actually part of my body, try and detach them from who I am.

Colvin: Not everyone will go on to develop chronic pain, but what we need to try and do is flag up the people who are likely not to have pain that gets better. And if they have pain at six to eight weeks after surgery that's not really getting better maybe we should be trying to catch them at that point. The onus is on the patient at the moment to ask for help, rather than us actively saying we know this is a problem, how can we identify who has the problem, and make sure they get the help early, rather than waiting until the patient actually feels strong enough maybe to ask for help?

Because I think that's one thing that's important – when you go through cancer treatment you're maybe not able to ask for things, you're vulnerable, you're a patient. And it's maybe only when you've got through the cancer treatment and things have settled – and that might take a whole number of years, actually, before they say 'actually, this is not good enough, I have to get some help with this'. And I think the other thing with cancer patients, is sometimes they're just sick of coming to hospital, so maybe we should be trying to get the help out there into the community.

Evans: When you say getting help out there into the community, what do you mean?

Colvin: Making sure that GPs, those working in primary care, are aware that it's a potential problem, so that when they go to their GP their GP is asking about it. Or maybe it's the physio, or the practice nurse. And if they ask about it they know what to do, how to direct the patient, either with some basic self management, or maybe just start some basic medication that might help manage things.

Evans: We're in Edinburgh today, but Maggie's Centres are around the United Kingdom?

Anderson: That's right. So you're sitting in the first Maggie's Centre which this year is 20 years old. And in 20 years we've developed 20 centres across the UK or internationally. So by the end of 2016 there will be 20 built centres, which is completely extraordinary for me to be able to say. I'm fortunate enough to have been involved with Maggie's for the last 18 years and to see that growth has been hugely refreshing and rewarding, but incredibly

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surprising as well. All of our aim and ethos is about making sure that people affected by cancer have access to the best level practical and psychological and emotional support that they can have during and beyond their experience of cancer.

Evans: I live in Swansea in West Wales – the Maggie’s Centre is a fantastic looking building underneath the maternity ward. Could anybody go in there just for the experience?

Anderson: Without question! So although all of Maggie’s Centres are cancer support facilities, they’re also community resources and a lot of people just out of interest, to look at what is an extraordinary beautiful building, designed by Japanese architect Kisho Kurokawa. Go see it, go see the space outside, go see the space inside. Sarah and the team who work there would welcome you with open arms.

It’s a beautiful space and it’s a space that is designed to support the Swansea and West Wales community in whatever way they wish. It has a direct relevance to cancer, but the more people that know about the centre the more able they are to signpost friends, family, colleagues, people around to the centre, if they are affected by a diagnosis. So my encouragement would be, go visit.

Evans: And also just going to see and talk to people in any of the Maggie’s Centres, I guess, goes quite a long way to dispel some of those myths about cancer.

Anderson: I completely agree. And as you walked in today you would have felt an atmosphere that you may not have expected to feel. It’s a very up, very alive, very bright environment, which doesn’t have the assumed heaviness and distress of what most people have an imagination of what cancer might mean. So for that reason it’s worth going to any of the centres.

Evans: And you can find out more about Maggie’s Centres and their locations at their website which is maggiescentres.org. I referred to Macmillan Cancer Support earlier, their website is macmillan.org.uk. And I’ll just remind you that whilst we in Pain Concern believe that 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, your circumstances and therefore the appropriate action to take on your behalf.

Don’t forget that you can download all editions and transcripts of **Airing Pain** from Pain Concern’s website which is painconcern.org.uk.

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Now, we talk a lot in pain self-management about the glass that's half full as opposed to the glass that's half empty. Last words to Claire Tattersall:

Tattersall: You know I can have my down days like everybody, but as long as I wake up every morning, I have to take a disgusting amount of painkillers and medications, I've got a niece and a nephew who are three and one and they just make everything worthwhile. They make me smile, they make me get out of bed every morning and I try and ignore the pain. If I'm having a down day then my pain is worse. This morning I spent with my niece and nephew, so my pain wasn't too bad, 'cos they made me smile and gave me cuddles and told me they loved me. And if I hadn't been through all the pain and treatment that wouldn't happen.

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