

Airing Pain 102: Chronic Pain and Resilience

What can be done for athletes at the highest level in the context of chronic pain, and how one man with a spinal injury found himself “in the zone” through cycling.

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For top-level athletes, chronic pain can very quickly end careers. What preparations can be done to combat pain, and how important is patient engagement in rehabilitation? In this edition of Airing Pain, Paul speaks to chronic pain psychologist Dr Greg Clarke about how acute pain can turn chronic in the context of sport, and how the resilience of young athletes can sometimes be a hindrance.

Ten years ago, Ade suffered a debilitating spinal injury. Four operations later, he was told by a surgeon that there was nothing they could do. Paul talks to Ade about his decision to attend a pain management programme to educate himself about his pain, and how cycling helped him take control of his situation.

Ade has also set up a fund raising campaign, the 21 Days of Pain, to raise money for Pain Concern. He plans to cycle 100km every day for 21 days (2,100km!). You can find his website and read about his story here: <http://21daysofpain.org.uk/>

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 health care professionals. I am Paul Evans, and this edition's been funded by the Stafford Trust.

Adrian Hart: I have heard professional sports people talk about being in the zone, your mind is being distracted in such a way that you are not really aware of what's going on in your own body. You are so focused on what you are doing that's you are unaware of the fact that your legs are burning or you're physically exhausted.

Dr. Greg Clarke: There are people that I have worked with within the club that I believe if they were outside of a sporting environment would have chronic pain.

Adrian Hart: Just because somebody is able to do an activity or sport that keeps them physically fit it does not mean that they're not ill or they don't live with pain.

Paul Evans: Resilience is the ability to stay on track of something that is very important to you in spite of adversity that gets in the way. Within a chronic pain context, obviously pain is the adversity, and it can create barriers to all sorts of social and mental functioning. Now I know from personal experience that first to go when chronic pain strikes, are often the things that we enjoy doing the most and let's face it, which make life worth living - the hobbies, socializing, exercise, sport and in particular, sport at the highest level, is what I want to focus on in this edition of Airing Pain. Dr. Greg Clarke is a Clinical Psychologist working in pain, and he also has a role working within a professional football club. Now, to me, that's an interesting mix of two extremes, I speak for myself of course but

there are the physically *unfit* at one end, and the *super* fit at the other. Another difference that occurs to me is that top sportsmen and women suffer multiple injuries through their careers, but the level and speed of treatment is exceptional. So are there lessons to be learned from the way injuries to elite athletes are managed, that could be applied to the general population?

Dr. Greg Clarke: It's a very different environment certainly from an injury perspective. It's unbelievable the level of input that they do get but obviously they are seen as a financial asset to the organization, so again you know the investment is obviously done for that purpose as much as anything. I'm not so sure in sport this might be controversial, but I'm not so sure it's about the person's well-being as opposed to their value of being back on the pitch, and again I think in social support that a lot of these guys get as well is very good. You know a lot of support and I think that that's where when you look at chronic pain you know you look at the social aspects to that. I think that's where there's not always a great support for people at times

Paul Evans: Are we really talking about acute pain in sport as opposed to chronic pain?

Dr. Greg Clarke: In general we are, you know we are talking about acute injuries that there is a process that goes through that allows the healing. I would say there is a slight difference however in that though in the sense that there are people that I have worked with within the club that I believe if they were outside of a sporting environment would have chronic pain. So again it's similar interactions that go on between the professional and the player or the professional, the client, the patient, when actually you know I'll get physios coming up to me and the medics coming up to me saying that there's nothing wrong with this guy you know. We have done the scans this there's no problem. I'm then probably working with somebody more on a chronic pain level and again when you then tap into some of those cognitive you know behavioural processes you kind of recognize that there's probably something going on. Certainly levels of engagement in the rehabilitation process but you also learn there are secondary gains as well within sports are being injured you know a lot of these guys are fearful of being released. Well if I don't play you can't judge me and if I then get released it's because of my injury rather than my ability as an example within a social context for chronic pain. If the reason for me not being able to engage in work is pain what happens then if we're saying well actually we'll take the pain away and then you can engage in work, but certainly within sport I think there are secondary gains to injury we do know from a social perspective, there can also be secondary gains you know in terms of physical health conditions as well.

Paul Evans: So you are coming from the world of pain management going into that world of sport, one of your roles would be to stop an injury developing into chronic pain?

Dr. Greg Clarke: Absolutely, and for me I think that that's maybe where we miss a little trick within the medical profession, all chronic pain was originally an acute pain and I struggle with this

differentiation between the two because I think chronic pain is maybe a representation of a different reaction to an acute pain. For me as a psychologist I believe we should be doing more in the acute world. I give a bit of personal experience, I've had lots of operations from my sporting days, and about three years ago I had a an operation quite severe one on my knee, and I remember sitting in the recovery afterwards in pain, quite significant levels of pain, particularly as I then thought I'd be a really good psychologist and avoid using any of the opioids and be mindful about my pain which was achievable, but I always remember from the experience in two older gentlemen opposite me who had had hip replacements and were clearly in pain, and when they requested support the first port of call was medication. You know to help relieve that pain and always remember thinking maybe that could have been an opportunity even pre-op to provide people with those skills or techniques is probably a better word of being able to just manage that pain in a slightly different way, and I guess for me that's where I always had this thought are we are we helping those people who are at an acute level, because maybe we could be making a difference and I think in the rehabilitation side of things you can get to different people with the same operation and actually somebody that I worked with their level of catastrophizing around the pain and about how their leg felt sent them down a more chronic path because they didn't engage in the rehabilitation, because of the pain whereas somebody else who I know who still experienced the same levels of pain but their perception was this pain is indicative of progress it's not necessarily indicative that I'm getting worse and I think that's where we could really help out more in an acute sense.

Paul Evans: I guess in the world of sport you are dealing with people up to the age of 30. So how do you get over to these young people, well young as far as I am concerned young people who want to get onto the field but I that there could be trouble ahead if you don't do it my way?

Dr. Greg Clarke: I think that's probably the biggest challenge because you have young individuals you know, and as we all know when we are young you know, I always say when I was 16 I knew everything and then you get to 20 and you realize actually I didn't know what I know now, and then as you get older you realize I still don't know anything. So we're working with individuals that are quite rigid in their approach in the first place. They are very determined individuals you know and as we know with a lot of teenagers they generally think they're right. Sounding really old now because I was one of these people that knew I was right at that time and I think that the big challenge is getting them to identify there are going to be challenges along the line, but I think going back to the mentality of sports and elite sportsmen they are quite unique individuals, their level and if we're going to use the word resilience or determination is abnormal you know they go beyond why I think most people would go through in terms of the level of criticism, the level of barriers that come up and actually the more I work with those elite athletes there, their mentality, their psychology is so flexible, so adaptable and I think that that's what makes the difference is their ability to do that so what we're trying to do. I also work with some of the younger players that might be a little bit more rigid in their approach or

defensive, so we teach them how to sit with some of that discomfort sometimes to enable them to still move forward in their career.

Paul Evens: So what do you take from the world of sport into the world of pain management for normal people like me?

Dr. Greg Clarke: I have yet to meet a normal person, I must say exactly is that I mean when we define normality I said I think what I've learnt and certainly kind of synthesizing the two of the world of sport and health is that we are actually going back to each saying we are all normal human beings, and actually irrespective of the environment the context we're in or the arena that we do things, we all react psychologically not the same but as a process and I think what I've realized is having worked with in the sporting environment and seeing people that whether we term it very resilient I think we also see that within the pain world as well actually we probably see 10% of the chronic pain population because there are 90% of people for example out there with pain that we don't hear about for me. From a personal level as well going back to my example it's being able to provide people with ways of managing pain that's just with you all the time and that's with you know having certainly worked with these people with chronic pain. It must be the most draining thing you can imagine you know I haven't had pain myself for a period of time, draining I think is a word that I quite like because it just wipes everything out and I think that that's where it's so difficult and I think if there's something that we can do to help people to change that pain to change the experience of pain so that it impacts less on them that can only be a good thing.

Paul Evans: That's clinical psychologist, Dr. Greg Clarke.

Now I want to introduce you to Ade. He has severe chronic pain following a spinal injury ten years ago. He lives with constant back and leg pain and, although he *can* walk, it was obvious when he came into Pain Concern's office, that it is with extreme pain. So, unable to work, he is now a stay at home dad to his eight-year-old daughter. Another thing that's worth mentioning in passing when he called into Pain Concern's office he was dressed in full cycling kit!

Adrian Hart: I'd had my fourth surgery and I saw the neurosurgeons who'd done the surgery and I was repeatedly asking them what can they do now what the next steps are. It wasn't quite as bluntly put but a more or less said I'm really sorry there's nothing more I can do for you, however we have a multidisciplinary team who I can discuss your case with and we can see what happens. From there I was referred to pain consultants who reviewed my medication and reviewed my situation and said that because I tried so many different medications there was no other options that they had for me. This was something that's I was just going to have to live with probably for the rest of my life, that's when it really hit home I remember saying to the pain consultant well I'm not going to give up, you know I'm gonna keep hope that you know even in the future somebody will come up with a solution

to take the pain away and I think in the end ended up doing that as best I could for myself rather than relying on more medication or more treatment. I think it was shortly after that that I was referred to the 12-week pain management programme at the Astley Ainslie Hospital where they taught me more about managing the pain. I think the course was a turning point in terms of me realizing that I've got to find my own ways and that was a very good starting point in finding my own ways to manage my own pain.

Paul Evans: Let me just go back a bit the Astley Ainslie that you mentioned that's a hospital in Edinburgh?

Adrian Hart: Yes that's right, they have a very good unit which deals with head injuries and the staff that work in the pain management program are actually working in the same unit as the people that work with people that suffered head injuries. I guess it's almost works hand in hand in a lot of ways, you're the rehabilitation of head injuries in terms of psychological hurdles to get over.

Paul Evans: I guess its teaching people to live with their condition

Adrian Hart: Yes they did a really good job, there's a lot of the techniques that we've talked about in previous episodes of the podcast about you know pacing and using meditative techniques, and that kind of thing to find ways to almost distract yourself.

Paul Evans: How were you referred in the first place the pain management program?

Adrian Hart: I had been to see the pain consultant and went back to my GP a few days later to actually discuss antidepressants, he then said we could talk about that another time but in the meantime I want to refer you on to the pain management course because I've heard really good things about it and I think you're a prime candidate.

Paul Evans: Why did you think that antidepressants were the answer?

Adrian Hart: It wasn't so much pain related, I think it was just because the way I was feeling at that time I didn't think I could get myself into a position where I was going to be able to try and find some kind of normality because of the really low moods and being quite uncommunicative with my family and things, and I found that the side effects were actually worse than the pain that I was trying to treat, so my wife said you need to go back and ask your GP for something else because you barely spoken to me for four days.

Paul Evans: It's interesting that your wife was saying this isn't working for you, the support of a partner is very important.

Adrian Hart: Oh yeah much so, being a very lucky in that respect that not just my wife but my whole family are very supportive, being a stay-at-home dad you know if I'm having a flare-up or something like that and I physically can't look after my daughter whatever, then I can always phone somebody, and if I'm feeling low or you know there's always people that I can phone and family is fantastic for that, and my wife is amazing, she goes to work five days a week often works late and still comes home, and I have not done the dishes or cleaned up or whatever and not cooked dinner because I'm struggling that day or whatever, and she still comes home and cooks and cleans and yeah she's amazing.

Paul Evans: OK so your GP very forward-thinking sent you into a pain management program, you know just explain to me what a pain management program is?

Adrian Hart: It was 12 weeks of half-day sessions which was a mixture of education about what pain is, the actual physical reactions that happen in your body which cause pain, or your mind and the triggers can either cause pain or influence how much pain you feel, and there was education on how to manage pain using various techniques, such as meditation, pacing, mindfulness and basic stretching techniques, and then there was a lot of kind of discussion about how to manage your life on a day to day basis, you know simple tasks such as you know doing the washing up or cooking a meal or cleaning the house, or day to day things which everyone takes for granted, but when you're living with pain you can't do day-to-day tasks in one go, so things like breaking up doing the washing up into 15-minute segments and do a little bit go and lie down and watch a bit of telly, listen to the radio and then go back, and you know do some more just little things like that which almost sound too obvious but it makes such a huge difference in how we live our lives and when you're dealing with pain.

Paul Evans: But you have an eight-year-old daughter I mean sometimes kids don't follow the rules

Adrian Hart: No, I don't even know if there are any rules to be honest, but yeah my daughter is more perceptive I think than I realize possibly because she's almost grown up with it, now you know it's always been there for her you know, dad's always you know walks with a stick or needs a mobility scooter or whatever you know, so for her it's that just who I am as part of my identity, she's good at understanding that if I need a rest, I need a rest and I've regularly find myself lying on the living room floor doing a jigsaw with an ice pack on my back. and so you find ways to manage it.

Paul Evans: One thing about chronic pain and other long-term conditions is that it's not visible you've come in in full cycling kit, how am I supposed to work out that you have chronic pain if you can cycle like that

Adrian Hart: That's a good question actually that is something that I worry about. I worry that people make the assumption that I'm doing some kind of benefit scam or I'm just kind of whinging about having a sore back, or a sore leg, or whatever. I do get nervous especially when I meet people when I'm a cyclist and it's like well you don't look ill, just because somebody is able to do an activity or sport that keeps them physically fit it doesn't mean that they're not ill or they don't live with pain.

Paul Evans: he can't be in pain because he rides a bike, let's put this into perspective, you're not just wearing cycle clips with a basket on the front the bike this is the proper job, the road cycling job so how do you equate that with your illness?

Adrian Hart: The whole using cycling to manage pain. I almost discovered it by accident it came about as a way of getting myself out of the house and going to the GP, or round the park with my daughter it was a way that I could take control of the situation, and for a while I was almost house bound because I was waiting for a Motability car, the car that we had I couldn't drive because the seating position was too low, nearest bus stop was too far away for me to walk to, so I dug my old bike out the garage and I discovered almost by accident that actually after I've been for a bike ride the pain levels would wouldn't go away, but were a lot less can kind of decreased for two or three hours afterwards, so once I realized this I thought well if the more I cycle the less I'm gonna be in pain, so I then started riding for longer and longer periods at a time. until I was going out all day, riding a hundred miles, and once you find something that helps you ease the pain you can latch on to it you know it was doing more than the pain medication.

Paul Evans: You see when you told me this originally I thought all right it's a disc injury in the back obviously, he's sitting down in the injuries below like so there's no pressure on it, such a purely physical thing, but what your saying is that it's a mental thing as well?

Adrian Hart: Yeah it seems to be a mixture of the actual physical movement, the kind of rocking the pelvis when you are cycling is quite a gentle movement, and that seems to be really good for easing the back pain.

Paul Evans: So there is a physical element?

Adrian Hart: There is a physical element, and also it strengthens your core muscles, which adds more support to the lower back. The mental side is an interesting one, I heard an expression about

being in the zone where your mind is being distracted in such a way that you're not really aware of what's going on in your own body. I've heard professional sports people talk about where you're so focused on what you're doing that's you're unaware of the fact that your legs are burning or you're physically exhausted, or whatever, so when I'm cycling I'm concentrating on other vehicles on the road, other road users, and thinking about the route that I'm taking, where I need to turn, I need to eat you know every twenty to thirty minutes, otherwise I'm gonna run out of energy, where is the next good coffee shop, and there's so much going on in my mind that I forget that the pains there, and it always feels like the pain is gone, but it hasn't really, I'm just not thinking about it. It reminds me of one of the techniques that we were talking about at the pain management programme, and you mentioned visualization and meditation, it's another way of distracting yourself so you're not thinking about the pain, and cycling is you know it takes up quite a lot of your brain.

Paul Evans: All your senses are involved?

Adrian Hart: Yeah absolutely but also it's almost like you are swapping one pain for another, when you come to a really steep hill, it goes on right to the you know, off into the distance you know, uh you know and your breathing becomes something that occupies your brain or the you know the burning muscles and sometimes just plain exhaustion, but then that's just something else that distracts you from the pain. What was a really big surprise to me was the fact that if I go out and cycle a hundred miles I can then have one or two days where the pain levels almost disappear.

Paul Evans: Well that's interesting because my next question was going to be the after-effects?

Adrian Hart: Yeah it's something that I've never been able to work out, and I don't know if it's to do with brain chemicals or the physiological effects, so if I had a busy few days and feel the pain levels going up and up, and then I go out and do a long cycle it kind of nullifies the effects of having done too much activity or different kinds of activities for the previous few days, because of that I try and cycle as much as I can, pain medication only does half the job and I tried increasing the amount of pain medication that I take to the point where I almost overdosed myself, when you get to the point where the side effects become worse than the actual pain itself, but the pain isn't going away well what do I do if I can reduce my pain medication by cycling every day, and that's you know that's a huge bonus and I'm doing what I love it's great.

Paul Evans: Now starting on the 30th of April 2018 of course that may well be in the past depending when you're listening to this, Ade took up a personal challenge to help others share in the substantial benefits he gets from cycling, and the good news is that you don't even have to have a bike or even leave the comfort of your armchair to share in those benefits, he's donating the charitable proceeds of a mammoth bicycle ride to us in Pain Concern to carry on supporting people like himself and me

for that matter who live with chronic pain, check out his website it's 21 that's the numbers not the words 21 days of pain.org.uk no gaps 21 days of pain.org.uk and this is what it's all about.

Adrian Hart: The aim is to cycle 60 miles every day for 21 consecutive days, so that's about 1,300 miles in three weeks. I realized the other day that before this - two days before I'm scheduled to start I've signed up for an event where I'll be cycling 300 kilometers, which is 180 miles in one day, and then a week after finished the 21 days, I'll be cycling 600 miles in three days. so I'm gonna be pretty tired I think after that.

Paul Evans: Going back a little bit to what we talked about it earlier somebody who can do that and maintain they have a chronic pain condition. that must be very difficult?

Adrian Hart: It is, and it's something that I think a lot of people will probably have difficulty to get their ahead around, especially when the benefits that I receive are based on the fact that I can't walk properly, but that's physically two different things, and cycling is completely different motion, your legs are kind of going up and down, whereas walking legs are going forwards and back, and because of the nerve damage in my legs every step I take is stretching damaged nerves which is extremely painful. It's almost like their damaged nerves are being dragged through rough scar tissue which i think the kind of mental picture is bad enough, but it it's a difficult thing to prove especially with pain being invisible, but when you have to spend you know several hours a day lying down just to relieve the pain that builds up on a daily basis, that's what people don't see the fact that I have to lie down and rotate heat packs and ice packs every 20 minutes to bring inflammation down after of been out for a dinner or whatever.

Paul Evans: Now of course not everyone will be able to cycle 60 miles six miles or even six feet in one go, or even at all to be honest so as always I want to remind you that whilst we at 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 don't forget that you can download all editions airing pain from pain concerns website and YouTube as well I'll give the last words of this edition of Airing Pain to Ade and don't forget this website it's 21 days of pain.org.uk.

Adrian Hart: The big reason why I'm doing this challenge is, it's not just a fundraising thing this is a way of showing people that by doing something physical you can manage your own pain, you don't need to ride 60 miles a day, just going out and finding something that you can do which doesn't

aggravate your condition can be enough to relieve your own pain, and doing something that you can do yourself without relying on doctors or medical professionals.

Paul Evans: It can be as simple as opening a window and listening to a birdsong, anything that makes you feel good will help, and it's learning what those things are that maybe the pain management program taught you.

Adrian Hart: That's a really good point actually, it's for me because it's a physical activity that's what helps me, but yeah whatever you enjoy, listening to music or playing music can be enough to distract yourself, just finds something that releases that chemical in your brain which takes the pain or even just for half an hour it's a great thing

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