Airing Pain 137: Pharmacists and chronic pain (transcript)

How to prescribe and de-prescribe safely

Jim Huddy (GP from Cornwall): There are plenty of people out there that do need doctors, they do need medications, they do need specialists and that's absolutely fine. We don't want to interfere with that, but there's also plenty of people out there, that probably don't need the medical machine, but haven't had an *alternative* to the medical machine. Those people, we think, can be in a better, more wholesome, and safer place with non-clinicians.

Paul Evans (Pain Concern): And that from a clinician, intriguing, we'll see. The NICE guidelines for safe prescribing and withdrawal of dependence-forming medicines were published in April 2022. They followed on from a Public Health England report in 2019 that looked at five groups of medicines that are associated with dependence and problems with withdrawal. Those groups are:

- opioids
- Z drugs, which are used to help people sleep
- benzodiazepines
- antidepressants which don't actually cause dependence, but can be problematic for people to come off, and
- gabapentinoids, now that gabapentin and pregabalin had already been reclassified to come under controlled drug legislation.

This led to concern in the pain community that it would have a detrimental impact for people relying on them to live better with their pain.

Doctor Emma Davies is an advanced pharmacist practitioner in pain management, she was involved in setting those NICE Guidelines and was co-founder to *Living well with pain*, prescribing for chronic pain.

Emma Davies: The scheduling of gabapentinoids was brought in ostensibly because of the concerns around misuse of those particular drugs, and there's also been quite a significant increase in deaths associated with those medicines. Now we know that drug related deaths are not particularly associated with drugs which have been prescribed to the people who unfortunately die. The vast majority of drug related deaths are connected to substance misuse and poly-substance use. People will be using multiple different drugs, but we know that gabapentinoids are forming a larger and larger portion of those deaths now, and that was why that legislation was brought in. There was a concern that with very high levels of

prescribing, we were seeing a portion being diverted and then leading to illicit use. I think for people using those medicines on prescription where they are demonstrating benefit, there should never have really been any threat to withdraw medicines from those people.

It is really important, as with all medicines, that they are regularly reviewed and that where they are not actually helping people to do more; or they're not helping to reduce their pain; or where they are causing more problems than they're solving for any individual, that there should be a conversation between the prescriber and patient about where that risk benefit lies, and is there some value to that person in trying to, very slowly, reduce those medicines. But that should be seen as really as a separate issue I think to the legislation side of things.

Evans: One of the issues is that people prescribe certain drugs, opioids and other drugs, the dose will go up and up and up, and they're still with pain. So the question to the patient is, if you're taking all these, and you're still in pain, then, the drugs you're taking aren't working, we should come off them?

Davies: Yes, that would be the advice now. I think 20-30 years ago we assumed that these medicines would be helpful for the vast majority of people and that's why we saw such a change, I suppose, in prescribing and particularly around opioids. We know that opioids are very good for acute pain and end of life, and so an assumption was made that pain is pain, and so people living with long-term pain would also derive benefit from opioids. And of course, as time has gone on, what has come to light is that for many people living with long-term pain conditions, those medicines just are not helpful. They don't reduce their pain over time and the adverse effects of those medicines can prevent the person from living a good life even with pain, and the same with gabapentinoids, that we understand now they are quite limited in terms of benefit.

So, where somebody isn't showing benefit from having those medicines, and experiencing side effects, which we now understand much more, and which often manifest in similar ways to the condition that people are living with, we have a very confusing picture. But on a very basic level, if you're taking medicines and you've taken them for, say, three to six months and your pain is no better and you're not doing any more, then probably those medicines are not going to work for you and no further increases are going to be of benefit. On the other hand, they might cause substantial harm, and in those cases working with the prescribers to just slowly reduce one medicine at a time, not necessarily stopping altogether, may perhaps get you into a safer zone. So, we find a balance that starts to give some benefit without causing the level of harm that we would be concerned about. That would be generally better for overall health and well-being, and that's the approach that we would encourage.

I certainly don't advocate not offering medicines to people. Very often medicines form a relatively small part of management, but it can be a really vitally important part. If they do help to reduce pain, it allows people to take control of other aspects of their life to increase their movement for example, maybe to stay in work, to continue to socialise and do things that they enjoy doing. Where that is the case, we certainly shouldn't be taking medicines

away. But what we want to prevent is causing harm by either continuing medicines which aren't helping or by just continually increasing doses into harmful ranges where we know people you know will suffer, possibly more than they would do if they were living with pain.

But that has to come hand in hand with making other support available to people, and I think one of the big problems that we have is we know the medicines are harmful and we know we have lots of people where they're just simply not effective. But we don't have perhaps the right support in place to give those people other ways of living effectively with their pain, so simply taking medicines away without replacing it with that support is what concerns me. I think a lot of people within pain management, people with pain and practitioners too, know that reducing medicines has to go hand in hand with support to find other ways to live well with pain.

Evans: So, just pulling the carpet away from people is wrong. What sort of things could you put in their place once you've reduced those medicines?

Davies: So, I think the first thing to say is there might occasionally be situations where there is such overt harm being caused to somebody, that there is some degree of urgency to make that person safe and so reducing medicine sometimes may have to be in the absence of putting the other support in place. But that should be a rarity. What we should be doing is looking at supported self-management and access to other therapies. That could be physiotherapy, occupational therapy, or movements of some sort that the person enjoys. Also, we should be supporting people to understand their pain better, to make sense of it based on their own personal experience. So, not just a generic, 'this is what pain is', but 'this is what pain is, and this is how it sits in your context'.

The most important thing normally is to support people to understand their pain and then to find ways that work for them, and that's looking at what matters to that individual. So, what are the things in their life that they want to be able to do more of; what brings them joy; what do they want to spend their time doing and what support do they need to move towards that. For many people, it's just encouragement - other people to speak to. Peer support groups are vitally important for that. I think sharing experience is often at least as important as having mindful practitioners to speak to.

I think learning from other people's experience is really important, and those are the sorts of things that at the moment lots of people find very difficult to access. There was a good talk yesterday from the patient group here at the BPS about intersectional problems as well and differences in in accessing care. So, we know that certain ethnic minorities, for example, have great difficulty accessing healthcare services of any type, and we know that certainly in in pain there's large differences in cultural approaches to pain and how pain sits within a certain culture, that can then become a barrier to people accessing support as well. So, there's a lot of work to do looking across a range of different ways that we make support more available and also increase conversations around pain. To normalise pain a little bit more, I think.

Evans: We're at the British Pain Society Annual Scientific Meeting 2022, and from people I've been talking to, there seems to be a thread running through it and that thread is personalised pain management. We're all different and different things work on different people. So, how do you as a pharmacist get around those things, I mean, you know, what is the answer?

Davies: I think it is very difficult, but what I do as a practitioner is listen to the people that come to see me and I think that's the most important thing that any person working professionally with people with pain should do. So, that question of what matters to you is such an important question to ask, because that is going to be very different for every single person coming in. So, our approach after that has got to be focused on those things that matter to that person and how do we support them to move in that direction. I feel my job as a practitioner has changed over the years. I've been working in pain management for about 17 years now and I think when I started out the onus, I suppose, was on the practitioners to be telling the patients, what *they* needed to do. My approach has changed quite dramatically and I now see myself more in a coaching role, so I'm not here to rescue that person, I'm here to support them to work it out for themselves. What are the things that they want to be able to do, how do they see things changing for them. It's only once you've had that conversation that you can start to plan what needs to be put in place from my perspective, to help with that, and sometimes it will be medicines, and other times it will be something else. It could be having help working out their finances, for example.

So, those early conversations are absolutely the most important thing I think, it's one of the problems I guess, with guidelines. So, it's one of the problems with all NICE guidelines is we talk a lot in NICE guidelines about Individualised care, but how we actually put that in place in practice can be very difficult within the confines that we have to work with, and similarly, sometimes NICE guidelines get criticised for not being directive enough. But if we are individualising care, you can't then provide an A,B,C,D, of what you should do because that isn't going to be the same for everyone. That is not individualised care, so NICE guidelines are very often left to interpretation, and often I find it's not the guideline so much as the interpretation.

Evans: Or the headline?

Davies: Or the headline that comes out – absolutely! Sometimes the headline sounds really quite terrifying, and I think that's what led to a lot of the upset, particularly around the chronic pain guideline. The headlines that came from that did not really bear a huge resemblance to the content of the guideline. We have heard of some instances where the interpretation of the guideline in practice, unfortunately, would make members of the NICE committee quite horrified, because that certainly wasn't how the guideline was intended to be used. We've heard about people having medicines stopped. If you actually read the guideline, there's nothing in the guideline that suggests that that should ever happen.

Evans: That's Dr Emma Davies, advanced pharmacist practitioner in pain management. Back in 2019, I spoke to Dr Jim Huddy, a GP in Cornwall, about an innovative approach to reducing the high levels of opioids some patients were taking, which would lead to, in his words, higher levels of misery. That's **Airing Pain,** edition 123, still available to download from Pain Concern's website which is: painconcern.org.uk. Since then, he and pain consultant at the Royal Cornwall Hospital, Dr Keith Mitchell, have put together educational resources for prescribers on how to prescribe, and how to de-prescribe safely.

Jim Huddy: A very common question for us from prescribers is that, if I don't prescribe, what do I do? There's plenty that can be done, but prescribers aren't very aware of what can be done. So, we've just started a five-year plan to make people more aware of them and make them more available.

Evans: So, what are the alternatives?

Huddy: Well, the model that we are following is Dr Francis Cole's 10 footstep model. Francis is a retired GP and her life's work has been to do with the self-management of chronic pain, and she's distilled her work down to these 10 footsteps, and what that means is that if you research and analyse the things that patients need when they're in long-term pain. They are things like being more active, sleeping better, understanding what pain is and what it isn't, acceptance, goal setting, pacing yourself, jobs, relationships. So, what we are aiming towards is having those important patient outcomes available for people to kind of pick and choose as they wish, so it certainly ticks the personalised care box in the respect that one patient might need lots of footsteps 4,5 and 6. But another patient might need footsteps 8, 9 and 10, and we're hoping that if this five year plan goes well, that they'll be able to find access to their particular footstep of interest in their locality, close to home, and live a better life. That's the hope.

Evans: This sounds like supported self-management. Supported Self-management is not you as a GP saying alright, you're on your own, it's how you help that person to self-manage?

Huddy: Exactly, and we're aiming for a time when in fact, it's not medics who do this, because you know as well as I do that, GP's and medics in all spheres are completely maxed out at the moment. They don't have capacity to spend time with people who've got sometimes very challenging lives, and that does take time to gain trust and give the support that you describe. So, in our core team, we've got two social prescribers, Nikki and Kevin, who run the community interest company called *Imagine if*, which provides social prescribers to our primary care network and another one close by. And so what we are aiming towards is upskilling non-clinicians into giving the support that people need and thereby achieving de-medicalisation of chronic pain for those who can de-medicalise. There are plenty of people out there that do need doctors, they do need medications, they do need specialists and that's absolutely fine. We don't want to interfere with that. But there's also plenty of people out there that probably don't need the medical machine but haven't had an alternative to the

medical machine. So, those people we think can be in a better, more wholesome and safer place with non-clinicians.

Evans: How do you get that over to a patient? He or she might want drugs because they think that drugs are the way forward. How do you get over to somebody who's in that frame of mind that, well, actually, gardening through social prescribing or exercise will do more than the medication?

Huddy: Well, we've formed what we're calling a 'Pain Café' in Perranporth in Cornwall. So that's my GP surgery. Our social prescribers run virtual events, so an online Teams or Zoom meeting every six weeks or so, and the idea of this is that patients dial in electronically to a one-and-a-half or a two-hour session. The idea is this to be a non-clinically led group by our social prescribers and Sean Jennings, who's our expert patient, and we invite patients to dial into this online meeting where they can talk about their own experience and understand each other's experience. This is this is under the realm of peer support. But I think what's really powerful about this approach, and we're going to hopefully replicate this throughout Cornwall, is that rather than a peer group which is based at the local hospital, which might be forty miles away from where you live, this is a peer group of people that live in the same village or town as yourself. They've got a WhatsApp group. I sent them a photo this morning, actually showing them that I'm at the British Pain Society and everyone's really interested in what the group is doing and we're finding that they're arranging to go for a walk on the beach together or have a coffee with each other and the power of peer support is knowing that there's people around who are sharing the same problems and challenges that you've got in your life and that's very helpful and powerful to people to know that they're not on their own.

It's a very non-threatening zone where people can come, and we try and arrange speakers each time we have a meeting. So, the next meeting, we're going to concentrate on Footstep five, which is about moving more or activity or exercise or whatever you want to call it. So, we're going get our activity specialist, Jamie, to come and talk to the group and explain, even if they can't do much activity, how they can do a bit more and get a bit fitter.

Evans: Dr Jim Huddy. Earlier we heard from advanced pharmacist practitioner in pain management, Dr Emma Davies. Now, it's my shame I didn't know until speaking with her about the diverse and essential roles pharmacists have in pain management. After all, doctors prescribe and pharmacists hand the medicines over the counter. Don't they?

Davies: There are huge array of pharmacists working in lots of different specialty areas who people do not know about. So, most people, when they think of pharmacists, they think of a community pharmacist working in a shop, dispensing medicines and offering advice around acute illnesses and minor illnesses. But pharmacists have a wide array of roles across all sectors of healthcare. I think people are probably becoming much more familiar with seeing a GP-based pharmacist. So, pharmacists are doing a lot of the medication reviews in practices now, and consequently, are starting to take on that medication review of those more complex medicines such as opioids and gabapentinoids. A lot more pharmacists are

therefore working much more closely with people with pain. So, it is a burgeoning area of pharmacist development at the moment.

Evans: Explain to me what a medicines review is and how important it is.

Davies: Medication review should really be an ongoing process for lots of people. They might be more familiar with perhaps being called in once a year by their practice, or maybe having a phone call over the last couple of years, often from the practice pharmacist, but sometimes it's the GP, or practice nurse. The idea of medication review really is to go through all the medicines that you might be taking for any condition and just checking that firstly, you understand why you're taking it, that you understand the doses that you're taking and checking that that you are taking the prescribed dose. We check for any problems that you're encountering, such as side effects, or other problems that you're experiencing that you might not realise are a result of your medicines, and also checking to make sure that that medicine is still needed. So, that's particularly pertinent in pain I think.

So that is an opportunity, if you are taking medicines, to raise the fact that you still have pain or that your pain has improved actually and maybe you want to think about reducing your medicines. Perhaps something was working, but no longer seems to be working as well and it's an opportunity to see, whether there is room to make a dose alteration or is there something else that could be offered, such as another medicine, an alternative therapy, or an appropriate referral or other support from somewhere else.

Evans: And it could be, especially as we get older and I include myself in that, and for people with chronic pain that different medicines are prescribed at different points. So, you could be stacking up medicines over and over again, you know, I'm constipated, right well we'll give you a medicine for that. I can't sleep, right, we'll give you a medicine for that. A pharmacist could look at that and say, well, actually this prescription is doing that, that is doing something else. If we took out that, or juggled those around, we'd stop the conflicting problems with it, and a pharmacist can do that?

Davies: Absolutely, that is such an important role for pharmacists. So, internationally pharmacists are recognised as being medicines experts and we are the only profession who have specific training and education around medicines and how they fit with disease management.

And you're absolutely right that very often people end up on, say, six medicines for conditions and another six medicines to manage the side effects of the first six, and as you say, sometimes when you see different specialists, they focus on their particular area. So, you might see a cardiologist, they just look at your cardiac drugs, you see the pain specialists, they just look at the analgesics and they don't perhaps always know or understand how those medicines work with each other or against each other in lots of cases. But that is the pharmacist's job to unpick that with the patient. So by having a really good conversation about how the person is, how they're managing symptoms, the pharmacist

should be able to work backwards to the medicines and work out are any of these problems being described actually caused by the medicines. In the case of pain, have we actually reached the limit of the helpfulness of these medicines, and they're now starting to crossover and become unhelpful for this person, and that's where we might have conversations then about, is it worth thinking about making some small reductions to your medicines to see if some of these problems are alleviated, pharmacists are absolutely brilliant for having those conversations, and that's a big part of the job now.

In England they've introduced structured medication reviews, and one of the topics is dependence forming medicines. So that does become an opportunity for people living with pain, who perhaps have been on medicines, such as opioids or gabapentinoids for some time, to actually have a really good, thorough review of those medicines and perhaps work with the pharmacist to make some changes to see if things can be improved for them.

We have similar schemes in Scotland, Northern Ireland and Wales, and also I think it's important for people to realise that this isn't a one off thing, so the medication review might highlight several things which need to be discussed or where changes need to be made, but those changes need to be made in a way that's manageable for the individual, so it's absolutely not about stopping everything. It's not about getting people off by next Friday. It's about working with the person and adapting and making small changes over possibly long period of time to get that individual into a better place overall.

Evans: So, the message has to be, use your pharmacist, go for your medicines review, it's free and you should do it regularly?

Davies: So, most people on long-term medicines should be offered a yearly medication review through their GP practice. Community pharmacists also have the facility to do some medication reviews, but of course if you have any problems with your medicines and you're just not sure who to ask, your community pharmacist is always a really good first place to go to, and as you say, they're a free service. You just turn up and they see you, no appointment necessary, and it's the beauty of community pharmacists and why we really need to value them, and there's a number of schemes now to increase the knowledge and skills and confidence of community pharmacists to support people living with pain. It could be some-one with an acute pain that's come on over the weekend, who pops into their community pharmacy during the week to get some advice, or people on long- term medicines. So there's a lot of work between GP practices, medicines management units, clinical commissioning groups and community pharmacists to try to increase the opportunity for people to have those discussions about their medicines in whatever setting suits them best.

Evans: Pharmacist Dr Emma Davies. As in every edition of *Airing Pain*, I'd like to remind you of the small print that whilst 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.

They're the only people who know you and your circumstances, and therefore the appropriate action to take on your behalf.

Now it's important for us at *Pain Concern* to have your feedback on these podcasts so that we know that what we're doing is relevant and useful, and to know what we're doing well or maybe not so well. So, do please leave your comments or ratings on whichever platform you're listening to this on, or the *Pain Concern* website, of course, and that's: painconcern.org.uk, that will help us develop and plan future editions of *Airing Pain*. Now, earlier we heard GP Jim Huddy extolling the benefits of attending the Perranporth Pain Cafe. So, to end this edition of *Airing Pain*, the healing power of a good book, and yes, you heard it here first, wait for it, the sniff test.

Huddy: Last time we ran these events, we had a guest speaker who's got a book sniffing club, which is about sniffing books [laughs]. It's a strange sort of subject, that you wouldn't expect to be the topic of conversation, but everyone really loved it and they chose an old book, it's not so good with a new book! You know, we were all having a good old sniff and explaining the sort of thoughts and feelings that we got from doing that. I must say a lot of people were much more eloquent than I was. I think I started sneezing because it was rather dusty the book that I had, it was a really enjoyable time I think for everyone to just escape from their day-to-day lives, which can be not much fun, a lot of the time. So, it's a bit of fun. It's meeting other people close to you who share your experiences and uh, having some distraction and a break.

End

Transcribed by Owen Elias

Registered office:

62-66 Newcraighall Road

Edinburgh EH15 3HS

Registered charity: SC023559

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