

Airing Pain 121: Living with Persistent Pain in Wales

Discussing the future of chronic pain services across Wales

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In April 2019, the Minister for Health and Social Services in Wales launched the guidance document 'Living with Persistent Pain in Wales.' Later, in December, the Chronic Pain Policy Coalition brought together some of Wales's leading pain experts at the home of the Welsh Parliament (or Senedd Cymru) in Cardiff, at an event chaired by Neil Betteridge, co-chair of the Chronic Pain Policy Coalition, a group which brings together a wide range of chronic pain stakeholders including professional bodies, patient organisations, parliamentarians and industry representatives from across the UK.

*This edition of **Airing Pain** was recorded live at the event, where clinicians, academics, policy-makers and people living with pain came together to discuss both the new document and the future of chronic pain services across the region.*

With thanks to the Chronic Pain Policy Coalition, the Welsh Government and the conference organisers for facilitating the recording of this event.

Issues covered in this programme include: Arthritis, availability of pain services, education, equality, exercise, fatigue, fibromyalgia, chronic primary pain, funding of pain services, GP, opioids, osteoarthritis, physiotherapy, policy, referral scheme, rheumatology, society, policy, visibility and Welsh government.

Paul Evans: This is **Airing Pain**, a programme brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain and for those who care for us. This edition of **Airing Pain** has been supported by an educational grant from Grunenthal. I'm Paul Evans.

Mary Cowern: There's up to 20% of adults living in pain in Wales every single day and arthritis and related conditions are actually the biggest cause of that pain as well. And half of

those people who live with that say they experience pain every single day. Eight out of ten say they experience it most days as well. And it's not just short term or a one-off burst. It's constant consistent pain, and it actually never ever truly goes away.

Evans: In April 2019, the Minister for Health and Social Services in Wales launched the guidance document 'Living with Persistent Pain in Wales.' Later, in December, the Chronic Pain Policy Coalition – that's a UK-wide coalition of professional bodies, patient organisations including Pain Concern, parliamentarians, and industry representatives, brought together some of Wales' leading pain experts, people living with pain, and other key stakeholders at the home of the Welsh Parliament, or Senedd Cymru, in Cardiff. The meeting was chaired by co-chair of the Chronic Pain Policy Coalition, Neil Betteridge. But for the background of the guidance, here's Ann Taylor, who is Professor of Medical Education at Cardiff University School of Medicine. She was the lead author of the Chronic Pain Directives in Wales published back in 2008, and she advises the Welsh health minister on pain matters.

Ann Taylor: It was developed with a wide range of Welsh Government officials, clinical and academic partners, and service users collaborating together to provide guidance that works for those requiring treatment as well as those receiving it. The aim of the guidance is to increase the focus on helping and supporting people develop skills to enable them to manage their persistent pain for themselves, whenever and wherever they need to and this will increase their ability to stay in work and live the lives that they want to live. The guidance was published in May 2019 and it was issued to a wide range of stakeholders including health boards, third sector and health organisations, and the steering group advised to allow a six-month period for the guidance to actually bed in within the health boards. To oversee the pain-related work going forward, the Welsh government has proposed a new advisory committee which will look to amalgamate the three advisory groups currently in existence. The advisory committee will then be tasked, and providing the minister of health and social services with well-informed, evidence-based arguments devised by those providing and receiving treatment. with the aim of ensuring that Wales is on the forefront of providing the best treatment, by the best people, at the best time.

Neil Betteridge: Welcome. Good evening ladies, gentlemen, friends, colleagues. My name is Neil Betteridge. My own personal and professional journey, if you like, with chronic pain goes back a long, long time because I was only three years old when I was diagnosed with

juvenile arthritis which had a very disabling effect on my childhood. So, later in life, professionally, it's been a great honour to get involved with organisations like Arthritis Care which, as many of you know, has since merged with Arthritis Research UK to form Versus Arthritis and that's one of the organisations we have speaking with us tonight. I've also had the honour to work with EULAR: the European Rheumatology Society, for the last twenty years on public affairs policy issues, but really trying to represent the voice of the person living with the condition.

You know, chronic pain, whether it's attached to a specific disease or whether it's a stand-alone condition that has no other disease directly associated with it, affects an enormous amount of people, often very severely, in ways which place a great personal burden on them, their families, their loved ones, but also on the wider economy and society. So we all collectively, I think, have a duty to work out how best and how better people with persistent pain can be supported to do the things they want to do, because that's a win-win for society as a whole. I'm here tonight representing the Chronic Pain Policy Coalition. My co-chair Martin Johnson is in the room somewhere. Martin is a GP. My background, as I've said, is as a patient representative or service user representative. So, we're trying to organise the coalition in a way which we believe reflects the best, modern, progressive approach to healthcare in any setting, which is healthcare professionals and patient representatives working in partnership as a team, and whether that's in the clinic or wider in policy terms I think this has to be the way to go. The coalition is UK-wide, so Martin and I, we don't live in Wales, we're not the experts about what's happening here. You guys are that. But what we aim to do is to provide a platform to facilitate and bring together healthcare professionals, patient organisations, public sector workers, a whole range of people with a shared interest in chronic or persistent pain, and let's not worry too much about the distinction there, I think it's the same thing although we may have preferences for the words, to see what it is that we can do better going forward. And I think we're all very impressed with a document which came out here in April, 'Living with Persistent Pain'. It sets out some fantastic aspirations, things we should all be working towards collectively, and I think [we] probably are at the stage now to see what that means in practice and how we can actually take those laudable aspirations forward and really make a difference to the lives of people with persistent pain in Wales in a way which is supportive of a sustainable health economy because that's essential too.

So, the series of speakers we'll have tonight, a few minutes each, are here to present a

range of perspectives on this topic. So, no more ado from me, except to introduce the first of our speakers which is Professor Ernest Choy, who is Head of Rheumatology here at Cardiff at the University Hospital here. Ernest is a distinguished rheumatologist clinician at the global level. And Ernest, I know you're going to be speaking specifically on fibromyalgia, but on this whole area of painful conditions I don't think we can have a more distinguished clinician to start this off. So, Ernest, please. [applause]

Ernest Choy: I'm a rheumatologist and most of my patients who come to my clinic were referred to me because they have pain somewhere in the body and usually pain that lasts for a significant period of time. More than ten years ago I bumped into a researcher in the corridor and he showed me a new imaging facility, which opened a new possibility for us. He showed me a functional MRI scan, which for the first time [it] meant that we can objectively assess patients' brains when they experience pain, and it opened up the era of research for me because in the past when the patients said that they had pain, you either believed them or you didn't, but you couldn't evaluate objectively what that pain was. So, in the first study of using that scanner, we showed that actually patients with fibromyalgia or chronic pain, that pain was real, the brain was showing them that they [were] having pain somewhere in the body.

So, from there on, we spent many years to find out that in fact the pain experience is incredibly complex. So, pain is fundamentally preserved in evolution. All of us don't have to go to school to learn about pain. We feel pain the moment that we [are] born. But that acute pain process is very important to us in protecting us. It generates stress, it generates emotion. The issue is that the brain actually is very active in managing and processing pain. And when you have chronic pain, it actually [means] that the brain is starting to fail to cope, and failing to cope leads to a chronic illness state. And that opened up a new area of research for us and more recently, we've been funded by Versus Arthritis to look at how [we] can we better help patients with chronic pain, particularly with fibromyalgia. And because we don't understand pain, the development of health services doesn't really map to the understanding [of] patients' suffering and healthcare professionals [don't] understand how to help these individuals because they can't evaluate the pain process.

So, we are going to do a series of work based on the health data we have in Wales, first of all to map out the patient's journey from the symptom onset to accessing different healthcare professionals. Having done that, we're going to interview patients to understand their patient

journey, interview professionals to understand how they manage the pain, and we will use more modern methods to model and develop a modern healthcare service for this individual, not only just involving doctors [and] healthcare professionals but also voluntary organisations, to get this patient to understand that there is a way out of this scenario for them, helping them to self-manage this chronic condition. And ultimately, once we have a model, we can go back to evaluate how efficient this model is, and hopefully to improve it. So hopefully this will be [an] iterative process and ultimately, we'll come out with a better management of patients with chronic pain. And I think throughout the journey, hopefully we will get involvement not only from our patients, but the public, but also different healthcare professionals because I think we all have a very important role to play in this process. Thank you very much. [applause]

Betteridge: Thank you, Ernest. And you mentioned there the important role of healthcare professionals and patient representatives working together to find solutions collectively. And we're here tonight to discuss all painful conditions, whether it's chronic pain per se, whether it's the pain of cancer, neurological conditions like MS or Parkinson's or arthritis conditions. But one of the ways I personally try to get the European Society – EULAR, in rheumatology, more engaged with the perspective of the person living with the condition, or the patient if you like, was to use the old civil rights mantra of 'Nothing about us without us.' In other words, if you're living with these conditions, these painful often debilitating conditions, you have a right to be at the table when decisions and discussions are taking place that affect you, affect your life and your care. And that means that we need good, experienced people who can rise to that and be the person to present that, and our next speaker is somebody who absolutely fits that bill. So, Mary Cowan from Versus Arthritis is somebody I worked with back in the days in Arthritis Care. Mary herself has lived for thirty or so years [with arthritis]. She developed arthritis when she was three like me, and has committed so much of her life and energy to the cause of helping people with painful conditions like arthritis. And Mary, we need somebody with your professional expertise in policy and public affairs to really sit down and work out, with policymakers and with health care professionals, the best way forward. So, it's a real honour to have you here with us tonight, Mary. [applause]

Cowern: Wow, I think he's bigged me up a little bit too much. I'm a bit worried now, but thank you very much for those kind words, Neil. So, I want to just talk about living with persistent pain and my connection with arthritis. As Neil said, I've lived with arthritis for a number of years. But I think want to touch on the fact that, you know, there's up to 20% of

adults living in pain in Wales every single day. That's a lot. That's a lot of people. And arthritis and related conditions are actually the biggest cause of that pain as well. And half of those people who live with that say they experience pain every single day. So just stop and have a little think about that. Eight out of ten say they experience it most days as well. That's a really hard deal. And I'm one of those people.

Every single day I wake up in pain. And it's not just short term or a one-off burst, it's constant consistent pain. And it can fluctuate throughout the day as well. And it actually never ever truly goes away. And I know from personal experience that that persistent pain of arthritis makes even the simplest things really really hard, really really exhausting, and excruciating. So, can you imagine now being able not to stand? All of you were standing here now, can you imagine you just can't do that. You can't walk. You can't hug a loved one because of the pain you're in. It's a challenge to be independent. Imagine not being able to remember what it's like not to live in pain. And that's our lives as people living with pain. But put simply, it steals from our lives as well. Any daily tasks that we all take for granted become really impossible. Imagine not being able to pick up a pen just because you've got so much pain in your hand.

Our spontaneity becomes eroded. Because everything you do, you have to plan for it. You can't be spontaneous. I had to not work this morning just so that I had the energy to be physically here with you tonight. Going down to the shops if you run out of a pint of milk becomes a huge mammoth task like just trying to run a marathon. It's really, really hard. Many of us have to give up work or reduce our hours. I actually stopped work for fifteen years because my pain and my arthritis were so unmanageable. And that robs you of a lot, not just your income but your self-esteem and your self-worth as well. So, it's not around, you know, just living in a bit of pain. It encompasses your whole life. Hobbies, social life, all become difficult. Three quarters of people in severe pain can't do those simple tasks. That's really, really high. Severe pain has a huge impact on fatigue levels as well. And living in pain completely exhausts you, it sucks the absolute energy out of you. The impact is that loss of normality. You don't become you anymore. You're someone else. You're this person living with pain, you get labelled. And it's that loss of losing the real you that you have to come to terms with. And as Ernest very eloquently said, it's not just about the physical pain, it's all the other stuff.

Yet the pain of arthritis and pain in general remains hidden. It's not always treated seriously

as we heard already. Everyday phrases like 'No pain, no gain,' or the glorification of the pain threshold that we hear quite often or, you know, 'Come on, just grin and bear it.' There's a culture there that exasperates that silent suffering for people living with pain as well. It prevents people from speaking openly and honestly about their pain and how they're feeling, something which is integral to actually taking ownership and managing your pain. Versus Arthritis, we identified that more than three quarters of people in Wales who live with constant pain don't say that, they hide it. They don't share it with others because they don't want people to feel sorry for them. And it's not about feeling sorry for you. It's about managing it and dealing with it. So just because pain is often invisible, and it's hard to describe, it's very, very easy for others to ignore it and pass it away. It's not understood and it's disregarded as a problem that needs to be dealt with. And it's not just about taking pills. As Ernest very eloquently said, it's around treating people holistically and taking a broader look about what's underlying with that pain, what other factors are impacting on it. But for many, many, many people we're hearing that it's just drug treatment that they're having, and they need care plans like me. That was the thing that worked for me. It wasn't just the drug treatments, it was taking a self-management and a very holistic approach to my treatment. Thank you for listening. Thank you. [applause]

Betteridge: Absolutely, and in terms of introducing our next speaker I'd just like to build on your reference to self-management. Because I noticed when the living with persistent pain document was published in April, there was a very precise reference to supported self-management being what is needed. And this is so important. Whether that's the role of the specialist nurse in oncology or the role of organisations like the MS Society, or whether it's other members of the multidisciplinary team, helping the person to live their life 24/7 – because that's what chronic or persistent pain is, it's a long-term condition which requires the person to manage themselves as best they can continuously – then nobody in terms of the healthcare professions provides greater support to many people in this situation than physiotherapists and it's an often overlooked, undervalued, neglected part of the multidisciplinary team. So it's with great pleasure I introduce David Easton, who's from Hywel Dda in Cardigan. I've probably just murdered a small section of the Welsh language, I apologise. My Welsh wife will kill me when I get home. But anyway, from Cardigan, David, who has an interest as a physiotherapist in the broader issues around pain science and management, is here to deliver the physiotherapy perspective. And as somebody who got back on my own feet, literally, as a child through physio largely, I particularly welcome your presence, David, thank you. [applause]

David Easton: I'm here to talk to you today about a specific evidence-based community rehabilitation project called ESCAPE-Pain that's been designed specifically for osteoarthritis affecting the hips and knees. I've been personally delivering this programme as a part of my role as a physio in Cardigan in West Wales for the last two years. And more recently I've been piloting a collaborative approach of this programme alongside my exercise referral colleague, which has resulted in seamless transition, [so] people [that] have [been] completing the programme [are continuing] to access community-based exercise classes.

Over the last five years, there have been a growing number of organisations offering this programme across all nations in the UK. There are currently over 260 active sites, the majority of which are based in England. Along with the four sites in Wales, there are two in Northern Ireland and there's growing interest in Scotland. The Health Innovation Network, the organisation behind this programme, has designed an accredited training programme to enable widespread scale-up and ongoing centralised support. I've arranged for key participant material to be translated into Welsh, so I believe this programme is absolutely ready to be rolled out more widely across Wales.

So why ESCAPE-Pain? Well, some influential academics in the field of pain management, namely Chris Main, Paul Watson and Michael Sullivan, in 2008 stated, 'We now have a large armamentarium-, ' I wouldn't have used that word myself, 'of interventions on which to draw, and while refinement may happen, emphasis should not focus so much on new techniques, but better selection and moving these interventions upstream to the start of the episode.' ESCAPE-Pain does exactly this. It's a programme that can be accessed through primary care. It can be embedded within local community services and provide access to good quality, practical advice and support. The broad inclusion criteria mean a wide range of people [in] [their] early forties right through their nineties and beyond can access this programme and this is essential for osteoarthritis because it affects people of all ages and at various stages of our life cycle. The research and national clinical audit data tell us that this provides good patient reported outcomes in terms of pain, function and quality of life for this highly prevalent condition. But not only that, we have evidence now that enables people to increase their physical activity and retain it beyond the programme. And this is very important because it goes to a long way to managing preventing many other common health conditions including heart disease, diabetes, depression, and cancer.

So that's why it's called ESCAPE-Pain: Enabling Self-management and Coping with Arthritic Pain through Exercise. So how does it work? Well, there are four key elements that [I've] identified [which are] critical to [the] success of this programme. Firstly, the number and frequency of sessions, so people attend twelve sessions over six weeks. Secondly, every session has exercise and education as a part of that and the education is using modern behavioural change techniques and communication styles, enabling people to identify the problems that they need to change in order to help them better adapt to this condition. And the exercise is personalised and progressive over the six weeks in order to optimise their outcomes. Thirdly, the group begin and end together. This is explicit recognition that people with long term health problems gain a great deal from connecting, learning and supporting others with similar difficulties. In some circumstances, the change that people experience can be rapid and dramatic, and this can be very helpful for others to realise and recognise that in time, there is hope for them in their condition. There's a strong sense of community among the participants within each group and for some this can last well beyond the length of the programme. Social isolation is an all-too-common problem for people with long-term pain. So, providing the opportunity for people to make new social connections within their community cannot be underestimated. And finally, what we do is we collect patient-reported outcome data and we share this with the Health Innovation Network. And this ensures that the positive research outcomes that we've identified are being transferred and maintained at the local level.

So what are the benefits to the health service? Well it's an effective intervention that goes beyond the programme. It prevents repeat referrals and visits to GPs, and it can reduce dependency on medication. Rolled out across Wales, if we work together with all relevant stakeholders with the hip and knee pain pathways, we could see a significant impact on the overall demand for healthcare interventions for osteoarthritis. Independent analysis by Public Health England has concluded that the return on investment for every pound that you put into this programme, you'll save £5.20 in healthcare costs. So what are the barriers? Why is it not more widely available? Well on the face of it, the length of the programme may appear too much for already stretched services to implement within their existing service model. But we all know it's time to shift our approach to more proactive methods within our health services, especially with complex and variable pain conditions such as osteoarthritis. Without offering the necessary time and opportunity for people with this condition to attain and retain the necessary knowledge and skills, we will fail to see the long-term benefits that this programme has demonstrated. Current services may also believe that they offer something

similar to ESCAPE-Pain already. But I would argue [that] when you look at these alternative programmes, they will lack at least one, if not more, of the four key principles I previously mentioned. So I would say that these programmes are not truly comparable. Neither have they been tested or scrutinised to the level of ESCAPE-Pain. And another issue for lots of rehabilitation services, such as musculoskeletal physiotherapy and community leisure services, is we don't have the financial resources to send staff on the training day to become a facilitator. This is key in order to make sure that we give good quality at the local level and we retain fidelity of the programme when we roll it out more widely.

So, what do I want to say to you? Well, my experience, and I'm sure maybe other people within this room already know this, [is] that actually building things up from the bottom is really hard. The things we've achieved so far in Wales has been in large part down to goodwill, and that's only ever going to take us so far. We've got the evidence to show the programme does work, and it presents a huge opportunity for large numbers to escape the repeat interventions, and I believe it merits wider rollout across Wales. The benefits are driven into many more service areas and physiotherapy and it needs leaders across the health sector to support and invest in musculoskeletal therapy and community leisure services to enable wider roll out. The benefits to these services may not be immediately visible, but we've proven they're there and that they are numerous. And for those in the room that may be familiar with the ten National Design Principles set out by the Healthier Wales document, to drive change and transformation in our NHS, hopefully I've been able to articulate that ESCAPE-Pain is pretty much ticking all of those boxes. Thank you very much. [applause]

Betteridge: Thank you, David. So, we've had perspectives then from a clinician, from a physiotherapist, and from the service user point of view, and we're turning now to a national perspective and specifically the nation of Scotland. And one of the joys of being part of a UK-wide coalition in chronic pain is when you can identify where progressive good strides have been made in supporting people with chronic pain. It's important, I think it's a duty on us, to try and highlight that to see whether there's learning that can be adopted elsewhere. So, our next speaker, with that in mind, is Paul Cameron who, on top of having an important job as leading the clinical pain service in Fife, is also the specialty advisor on persistent pain to the Chief Medical Officer in Scotland, and has provided great leadership and coordination to the National Advisory Committee which has been established there and which really has been doing and continues to do some great work. And I hope there'll be something here from the

brief glimpse we can get in the next five minutes Paul, that maybe, you know, here in Wales some learnings can be derived because it really has been tremendously impressive. So, ladies and gentlemen, Paul Cameron.

Paul Cameron: Thank you very much. So, I have five minutes to sum up about ten years' worth of work. So, I have to say right at the start when there was talk about a chronic pain service shutting down, and [I] was really, really sad to hear that but very angry to hear that because to me, that's a symptom of a complete lack of understanding about chronic or persistent pain, whatever you want to call it. It's a complete lack of understanding of what it is and how many people it affects, and [how] sometimes these services are seen as an added luxury when clearly, they're not. We're quite lucky in Scotland now, but we were probably in the same situation a few years ago. We had a number of reports written, which I'm sure has happened here before as well. People write very nice reports, they are printed off, sent around [and] they are added to the pile of other reports. They get put on a nice shelf, they collect dust, and everyone forgets about it unless they're writing an essay at some point for a masters. And that's what happened with us. We had several reports written over the years. What changed for us was a report called the GRIPS Report in 2008. It was published 'Getting to Grips with Chronic Pain, or Pain.' But that in itself wasn't the change because that was another report. It had a nice cover, I have to say, it was lovely in terms of looking. But the biggest change was that the First Minister, or rather the Health Secretary at that time, now the First Minister, Nicola Sturgeon stood up and said that she recognised chronic pain as a condition in its own right. Now that changed things dramatically for us.

[And] I suppose I've been asked to speak about the Scottish perspective and I think it's the same everywhere you go; in order to get these services improved and pushed and supported, it needs a national guide, it needs a national perspective. But not just a nice speech, but continued support and continued oversight, with agendas, with recommendations, with action points, and that's what we got. And it's what we have now and this is why we have a National Advisory Committee. We started off with a ministerial committee. Now that sat with a minister on there, the then Secretary for Health, and her job was to try and make sure that we pushed the agenda forward. That was great for us because you can't get any better support than having an MP or MSP sitting round the table. That pushed things dramatically. It created [not only] more reports but actually more guidelines. It put chronic pain on the agenda, on the national agenda. It asked for quarterly reports for waiting lists for pain clinics, so suddenly everybody wanted to know how we were

performing. And then of course the health boards, when they're asked for that type of information, suddenly they want to perform better. We were asked to do so many different parts but we created a document, the Quality Prescribing Document, for example, looking at realistic prescribing, at deprescribing, rationalising, prescribing, building in an audit into that prescribing, and that's being implemented just now. We looked at the measurement of chronic pain and what's called the National Core Data Set, we're building that as we speak. It's gone through two years of validation and it's now being put in the hands of our National Information Services Division who will be implementing that across the whole of Scotland. So we will start gathering more data than just waiting list data. On the back of recognising that actually most of pain is managed in primary care, we started to build resources in primary care. So we have leisure centres involved, we have Pain Concern, we have Pain Association of Scotland involved in pain management programmes. We have resources in every library in Scotland. We have so many different aspects, but it all started with a national support. And I think when I was asked to come and provide my Scottish perspective, my perspective is within the Welsh Assembly we should have Welsh national support. And with that support you should have continued markers, recommendations, driving it forward, looking at it, making sure it's happening, and looking to see what will make that happen. Thank you. [applause]

Betteridge: As you said, Paul, most persistent pain is managed in the community or in primary care. So it would be remiss, I think, not to have a primary care GP perspective here. So, it's my pleasure now to introduce Lucy Morris who's a GP partner at the Bellevue Practice in Newport. This is an incredibly important perspective because if we are to make real positive strides around the better management of people with persistent pain, their condition, then we absolutely need to get the full, integrated involvement of primary care. So Lucy, your perspective is invaluable here, please. [applause]

Lucy Morris: Thank you very much. I will say I do feel like a bit of an imposter coming here because I'm the only person that's not an expert in either having pain or researching pain. I've been working as a GP as a partner in Newport for over ten years now, the biggest practice in Newport in fact, we've got 17,500 patients. So, I do have a lot of experience of helping patients who are really genuinely struggling to live their lives with persistent pain. I asked one of my colleagues in the practice, who knows a bit more [about] how to work the IT systems than I do, to do some factfinding for me. And I've asked 17,500 patients. I wanted to find out how many of them were living with persistent pain. I had a feeling it was quite a few,

and of course the coding of these things is never perfect, but I asked him to search two main codes. We can either allocate a code to a patient if we believe they've got fibromyalgia. The other one that we use quite a bit is chronic intractable pain. And these codes allow us to search our databases and see how many patients are living with persistent pain. We came up with 388 patients on our list and I thought, 'Well, that's less than I thought actually.' And I think that's more to do with the fact that a lot of the patients living with persistent pain may have codes such as osteoarthritis or various other inflammatory arthropathies etc. So, I then tried to establish, 'Okay, well, how many of our patients are on long-term opiate-based, opioid-based analgesics?' So, pain relief that shouldn't really be issued to people who aren't either suffering with, you know, a short-term condition or palliative care or cancer pain. So we excluded those patients, and we found that nearly 1,300 of our patients are having repeat prescriptions of opioid analgesia. And that, I thought, was quite alarming considering that, I think, most of my colleagues and myself are aware that that's not best practice. So I think, 'Well, how does that happen?' We know that that's not the best way to manage patients who are living with persistent pain. And yet, here we are with well over 1,000 patients having these prescriptions month in, month out, and sometimes more frequently than that. It's another problem with patients perhaps overusing medication that we have.

And I think it comes down to the effect of GPs feeling overwhelmed a lot of the time, feeling that they don't have the resources to best support their patients. Most GPs want nothing more than just to make it better. It's not in our interest as GPs to try and be obstructive to patients, trying not to help them. If somebody comes to us in a crisis, we want to improve their situation. I see mothers who are in so much pain they can't pick up their young babies. I see people who are caring for people in persistent pain, every day children caring for parents in persistent pain and it's absolutely heart-breaking. And yet, when we look at the services available to us, when I started out as a GP, say for example if I had a patient who had a diagnosis of fibromyalgia, I would get some very useful information from my colleagues in rheumatology, or perhaps the pain clinic services would be able to offer some support. Over recent years, the burden on those services has become so great that they now, if I refer a patient who I believe has a diagnosis of fibromyalgia, I will get a very helpful letter back to say, 'We will not see this patient because there's nothing our service can offer for them. But here's some information about some drugs that may be of use and local services.' With the best will in the world, we know about those local services and we know about those medications. We're looking for almost a bit of bolstering, a bit of support for what we're doing with those patients. And it's the same with the pain services as well, they just simply don't

have the capacity to take on groups of patients where they don't believe they're going to be able to help much.

So, increasingly, we're dealing with patients with very complex problems but being entirely managed in a primary care setting when it comes to their medication management. We do have non-NHS services. We've heard a little bit from the other speakers about things like the National Exercise Referral Scheme, which is an incredibly useful programme that runs various different programmes for exercise support, not just for pain management.

Unfortunately for some of my patients, they just simply find the idea of being referred for an expert exercise programme overwhelming. And then when you also look at the rates of patients who complete the programme, I actually emailed to get some figures from them.

They came through to me today that, of the referrals last year in Wales, they had somewhere in the region of 1,350 referrals to the Exercise Referral Scheme. Patients who are still exercising a year later was less than 350, so the drop-off rate is quite significant as well. So, there is a lot of will to support these extra services. But I think embedding things in primary care, perhaps I do agree that we should try and move away from medicalising persistent pain and trying to support people to live in the community with it. But I do think a stepwise programme, where perhaps we have people embedded particularly the larger general practices, [could be beneficial]. We're having a lot of success diversifying our workforce population. In my practice we have nurse practitioners, pharmacists, more recently we've taken on a community psychiatric nurse, all working full-time in general practice so that patients, when they come to our surgery, no longer have the expectation that they're going to see a GP, but have the expectation that they will see the right person to help their particular condition. And I'd like to see more pain psychologists, or people who have expertise in supporting patients with these persistent problems, being embedded in the larger general practices to better support our patients. So, there is a lot of will to improve the situation from a primary care perspective, but still a long way to go. So, thank you for inviting me this evening. [applause]

Betteridge: So, we're pretty much through then. I don't want to give any platitudes at this point. I think you've all heard the specialist and generalist perspectives on this important topic. I hope it's given you food for thought. It looks, feels and sounds to me like Wales is in a position right now to take a big next step forward, a really important next step over this next period, to get this right for people with chronic pain, and I think they deserve that. Nos da ('good night'). [applause]

Evans: That's Neil Betteridge of the Chronic Policy Coalition who chaired this meeting about the new guidance document 'Living with Persistent Pain in Wales'. As always, I'll just remind you 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. He or she is the only person who knows you and your circumstances and, therefore, the appropriate action to take on your behalf. Now, you can find all the resources to support the management of chronic pain, including details of Pain Concern's helpline, videos, leaflets, all editions of **Airing Pain** and Pain Matters magazine at Pain Concern's website which is simply painconcern.org.uk. And rather than giving you a confusing, long, complicated web address for you to download the important 'Living with Persistent Pain in Wales' document, I suggest you just put that title, 'Living with Persistent Pain in Wales,' into your search engine. Here's Mary Cowern, Wales' Director of Versus Arthritis to end this edition of **Airing Pain**.

Cowern: The reality of it is the pain won't go away. We know it's not going to go away. We're not going to cure it, but we can manage it. And it's going to be different for everybody. And it'll be different for everybody in the way they manage it as well so it's important that people get the help that's right for them. So that tailored approach to their pain management, treating people holistically, hearing the whole story about their pain, can help them understand that pain better as well, and tailor that support that they desperately need. So at Versus Arthritis, we believe it's time for change, as I do. And I think the time is right in Wales for that change now as well. Let's stop people putting up with pain. Let's stop people ignoring pain. Let's change society's attitudes to pain and let people like myself be open and take away that silent impact of it.

Contributors:

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More information:

- The Chronic Pain Policy Coalition – chronicpainpolicycoalition.com
- Versus Arthritis – versusarthritis.org
- Welsh Pain Society – welshpainsociety.org.uk
- [*Living with Persistent Pain in Wales*](#) PDF guidelines.



Transcribed by Cara Manning-Diabira