



## Airing Pain 139: Living With Persistent Pain in Wales

**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, our family and supporters, and the health professionals who care for us.

Dyma Airing Pain, rhaglen a gyflwynwyd i chi gan Pain Concern, yr elusen yn y deyrnas unedig sy'n darparu gwybodaeth a chefnogaeth i'r rhai ohonom sy'n byw gyda phoen, ein teulu a'n cefnogwyr, a'r iechyd gweithwyr proffesiynol sy'n gofalu amdanom.

Enw i yw Paul Evans.

I'm Paul Evans.

*[applause]*

**Eluned Morgan:** Well diolch yn fawr iawn i chi, a diolch am y gwahoddiad I siarad gyda chi yn y gynhadledd gynta sy'n a wneud a poen parhaus yng ghymru. *[Translation: Well thank you for the invitation to speak to you in the first Persistent Pain in Wales conference.]*

So thanks very much for the invitation to come and speak to you this afternoon. I think this is the first Persistent Pain Conference for Wales and I'm really delighted to see such a varied representation of healthcare professionals here today. And I'm happy to have this opportunity to share with you some key updates in relation to persistent pain in Wales.

**Paul Evans:** That's the Wales minister for Health and Social Services, Eluned Morgan who on September the 18<sup>th</sup>, that's 2023, launched the revised Living Well with Persistent Pain in Wales guidelines. She addressed over 170 delegates, mostly health professionals, but some patient representatives including those of us from Pain Concern, and some service providers.

The full document is available to view online, you'll find the links on Pain Concern's website, but throughout the day I was able to eavesdrop on some of the conversations going on in workshops and talk to some of the service providers.



**Eluned Morgan:** September marks Pain Awareness Month and today represents a valuable opportunity to raise awareness of an often unrecognised aspect of pain, which is, of course, persistent and chronic pain. And what we know is that this condition affects a significant proportion of our population. I think it's estimated between 33% and 50% of the population suffer with some form of persistent pain. And that's up to 1.3 million adults just in Wales. So we are talking about a *lot* of people here. And these are conditions that can have a major impact on a person's quality of life, their ability to work, to function, as well as clearly their mental well-being. But we know that with the right information, support – collectively, we can develop pain services in a way that produces better outcomes and experiences for these individuals. And that's why the Welsh Government has been working closely with our partners in the health service, academia and those with lived experience to refresh the Living with Persistent Pain Guidance.

**Owen Hughes:** I'm Owen Hughes, I'm the national clinical lead for persistent pain in Wales.

**Paul Evans:** It's a refreshed guidance; what has happened between 2019 and 2023 that might need refreshing?

**Owen Hughes:** Well, I think there's, it *is* the obvious thing, it *is* the fact that COVID has made a massive difference to the way that we run, deliver services in Wales. It's made a massive difference to the way people live their lives. And so our role in terms of refreshing that is to acknowledge the fact that now people are using digital much more as a way of engaging with the healthcare services and also the fact that levels of digital literacy have also changed massively, by having to use Teams, Zoom and whatever to keep contact with people over COVID.

**Paul Evans:** It almost seems as if you would have had to tear out pages 45 to 90 of the previous ones and replace them with something else.

**Owen Hughes:** Well, the key elements are there. The key, sort of, ideas are very much the same. But what *has* changed is the opportunity for digital and for the things– At the end of the day, the document is about actually helping people to work *with* their healthcare professionals. And that's really what we want to be doing with it, is saying that pain management is not something that healthcare professionals do to people, or do to patients. It is something that people do *alongside* the healthcare professionals, working as a team and



very much working on whatever it is the individual themselves. Whether that'd be staying in work, spending time with your grandchildren, whatever, that's the core of this.

**Paul Evans:** How have patients been involved in the writing of this new document?

**Owen Hughes:** What we've done is had various focus groups as part of the thing. People have been invited to review the document in its various iterations over the years. What we want to do going forward now is to really involve people in the development of the services as we go forward. So we're in the process of setting up a people's panel for persistent pain, where we want to hear the voices of all sorts of different people who are affected by living with persistent pain. Both the people themselves, but also their carers, families, employers, communities. There isn't just one person, one sort of person who lives with persistent pain. There are people living in care homes who have persistent pain. There are people living in their own homes. There are people who are, you know, carrying on their normal lives and who aren't— who have come never come in contact with the health services. So we want to hear from them as well and understand what is it that actually helps them and protects them from having to come and see healthcare professionals.

**Paul Evans:** How can they get their voice heard?

**Owen Hughes:** We're always very, very pleased to hear from anybody who's got a story to tell or questions they want answered, so they can come direct to us – myself or Sue Jeffs, she's the other national clinical lead. The health minister is always interested in hearing from people who are living with various different concerns and the services and how they— both positive and negative stories about what's working. And actually that will always help us to keep the profile of pain high in Wales as well.

**Eluned Morgan:** Now this was first published in 2019 and we've received positive feedback, I think it's fair to say, on its use as a source that empowers individuals to better understand their condition and to become a more active partner in their own care. And as a tool to aid house boards to plan their persistent pain services appropriately. Now, it's important that this guidance continues to evolve as we gain more understanding of what works and where there's scope for improvement. Based not just on evidence, but on talking to people about their actual needs.



**Real City Strategy (RCS):** We are RCS, Real City Strategy based up in North Wales and we're running a project called the In-Work Support Services and we're running it across North Wales, West Wales and Swansea Bay and Neath Port Talbot area.

**Paul Evans:** So what do RCS do?

**RCS:** So RCS are a community interest company who support well-being, so we're currently running the In-Work Support service, but we do also provide well-being training and support to small medium enterprises and other businesses as well.

**Paul Evans:** And what sort of support is that?

**RCS:** So basically with our clients, what we do with the In-Work Support service is we're supporting clients who could potentially go off work through physical or mental health issues. So they're at risk of being in sickness, absence from work or struggling at work. So basically living well with persistent pain is part of what we're trying to help clients do. We work with clients with a range of different issues, but obviously a lot of clients do present with pain. We've recently been supporting clients with lymphedema, so there are an array of conditions that clients present with. We provide them counselling or access to physiotherapy or occupational therapy to help them manage their conditions and help them to stay in work.

**Paul Evans:** How do they get in touch with you?

**RCS:** So it's self referral. Anybody who's employed or self-employed over the age of 16. And the way that they can sort of get in touch with our service is via our website [rcs-wales.co.uk](https://rcs-wales.co.uk), they can e-mail or they can phone in to the company.

**Eluned Morgan:** We know that since 2019 a huge amount has changed. COVID has led to significant developments in how our NHS services are developed and used, including how we can develop and take full advantage of digital technologies to improve access and outcomes for the people that require care. And it was great to see recently an example in how of our health board watching people prepare for surgery – all done remotely – and the feedback from the patients was that this is really, really working for them. It's preparing them for operations. It did reduce their pain. It was all of these things. So this ability now for us to use this remote access, I think is absolutely transformative.



**Gethin Harries:** Enw I yw Gethin Harries, d'win gwaithio fel consultant physiotherapyf yn Bronllys yn Powys efo'r tim byw yn iach – the Powys Living Well Service. *[Translation: My name is Gethin Harries, I work as consultant physiotherapist in Bronllys, Powys for the Powys Living Well Service.]*

**Paul Evans:** Let me brush up on my Welsh. You're a physiotherapist working with the Powys Health Board in..?

**Gethin Harries:** In the Powys Living Well Service. And just to sort of give a bit of context, that is a service that supports people with persistent pain primarily and then also supports people with persistent fatigue. And also weight management.

**Paul Evans:** Let me put Powys into geographical context. It's the biggest county in Wales.

**Gethin Harries:** I believe so, yeah. So I think, you know, from somewhere as high as Welsh Machynlleth in the north. Then you've got all the way down to Ystradgynlais. So, you know, you are talking almost, like sort of like a two hour window of driving. We know that in Powys anyone that comes to see someone in the face to face appointment, it's an average of about a 40 minute commitment for that person. So where we can, we will go digital first for that person, as we recognise it can be easier for them and, you know, and we're obviously able to help more people across that time as well.

**Paul Evans:** So it's mid Wales, not in the industrial areas up to the borders of England, and up to North Wales almost.

**Gethin Harries:** Yeah, it's a huge variation of borders, and as you say they border across multiple health boards, multiple areas, England and Wales.

**Paul Evans:** So it's a long drive for anybody who wants to see you. So digital is important to you.

**Gethin Harries:** Digital is important. As I said, we are making sure we come to people as able as well. So we are developing and we have developed a successful contract clinics in key areas. Newtown Ystradgynlais for ourselves but I'm in Bronllys, where we are. But yeah, digital is essential for people because if you think about it as well, when we're living with persistent pain, the discomfort associated with the long driving, the energy taken to commit



to an appointment like that means that hopefully people can have a better quality time with us during that conversation.

And during that physical assessment, as we can do digitally, if we need to. Yeah, we're talking about rural Powys. So although we have a fantastic, fantastic digital team, if it was someone sat somewhere with really poor digital access, we can arrange that maybe they can have that support from iPad loan, have the right network put in place with the right apps, they're ready to go for them. They could come to their local library or other local buildings, so they've got somewhere safe to have that appointment, if it's different to where they would be at home.

So as you say there could be online resources that they look at in their own time. Or it could be a programme that they join in a virtual setting with other people across Powys, so they're able to not only learn, hopefully, some of the hints and tips from us, but also learn from each other. Because, you know, they're the experts, they're people living with long term persistent pain. We can show our empathy of that awareness of what we are as clinicians, but actually you can't beat that conversation of learning off each other and what, you know, what works well and what doesn't work as well.

**Paul Evans:** What do these updated Wales Persistent Pain guidelines mean for patients?

**Gethin Harries:** I really hope for the people that we're seeing, they recognise that there are multiple choices. It's not just about traditional previous medical models, interventions where, you know, maybe there's a perception maybe that we would have medication as a primary treatment or other interventions. That the people are aware that the menu is actually quite vast. And that people want to improve the physical health, psychological well-being as well. Because it's extremely distressful to be living with persistent pain, and there's multiple options there for them. And hopefully by people having access to this new document they feel able to be armed with the knowledge, I guess, that they can access multiple services. And what you're seeing across health boards, you know from Hywel Dda to Betsi, is that—oh, Betsi Cadwaladr in there, sorry, all the way up. Is that you've got a variation of those services all going— following hopefully the core principles of these documents. But the variation is probably more to make sure that it's fitting with the people and the areas that they're living.



**Eluned Morgan:** Now the aims set out in this document very much align with our national strategies for a healthier Wales. The Welsh Government's programme for government and the principles set out in the Well-being of Future Generations Act. By putting a focus on *prevention* and helping people to stay active and independent. And really importantly, empowering people to do more to manage their own conditions. And I'd like to use this time to draw out some of the key things of the guidance. So there are five key parts of that. First of all, the central role of co-production. What is key is to encourage a conversation between people and healthcare professionals using a biopsychosocial approach that considers the whole person, not just the medical issues. So it's important for us that people feel listened to and this approach shifts the focus to what matters most to the individual, their everyday tasks and concerns, and helps to set reasonable and achievable goals.

**Sophie:** My name is Sophie. I am the Education Programmes for Patients project coordinator within Cardiff and Vale University Health Board.

**Paul Evans:** Now the Education Programme for Patients, EPP

**Sophie:** Cymru.

**Paul Evans:** Cymru. Which is Wales.

**Sophie:** It is, yeah.

**Paul Evans:** That used to be known as the Expert Patient Program.

**Sophie:** That's exactly true, yes.

**Paul Evans:** And I went on an expert patient program 12 years ago. And I found it absolutely fantastic. No healthcare professionals. Helping me and other people to live with long term conditions.

**Sophie:** I think that sums up this part of the podcast. *[laughs]* I think you've done it, yes. I'd just like to reiterate that it's exactly it, really. And like you, I attended a course maybe about 13 years ago now, and part of the reason as to why I attended was I live with a mental health condition. And part of my recovery was medication and the CMHT, which is a Community Mental Health Team. And at the time I had a community psychiatric nurse that was helping me sort of manage my condition in the community. And at the end of that course of clinical



intervention there really wasn't much else apart from - I found out about the Expert Patient Program. And I remember thinking, "what's this self management?" And for me, when I attended, I thought it was all going to be about my condition. Until I realised that actually there were people living with a range of health conditions on this course, from Parkinson's to depression to - what then was, we knew was ME - or was *then* described as chronic fatigue. We know a lot more now. But there was an awful lot of health conditions and I didn't realise at the time that the Education Programme for Patients was actually an evidence based, research based self management program that was designed to help, as you said, support people to live more effectively while managing long term health conditions that we now know have no cure. And that accepting that self management is part of the process of living some form of life after your diagnosis is really integral to managing in the communities. Which is where we get the most reward and is the most nourishing around our loved ones, in our workplaces, contributing to friendships, to relationships. But without self management I wouldn't be able to do those things as effectively now.

**Paul Evans:** Those words, "self management", they have to be explained, really. It's not a cop out: "go away and look after yourself." It's supported self management. Helping you to live with your condition.

**Sophie:** I didn't think I needed help to learn how to do that, but I clearly did and that's really key, actually. Yes, it is supported. And what was interesting was that the courses, all of our courses, are ideally facilitated by volunteers who live with health conditions themselves. So as you rightly said, there's not a clinician in sight. So it is people who have accessed the course that clearly feel it has helped them, wanting to give something back. So then they go on the training to be able to facilitate the course, usually now with the condition specific that they access the course with and then they have decided that, actually, I'd like to give something back and I'd like to maybe support another group to live more effectively while managing their health condition. And there it goes then, group on group. We use the term "lived experience" and "peer support", but I don't think those words were used. It was just people wanting to learn ways to manage coming together and just sharing that experience. We now have terms that people can associate with, and that is truly lived experience, isn't it? That you've lived a program. It's been beneficial and you want to help support somebody else manage more effectively.





**Paul Evans:** But it's important to say that it's not just a group of people saying, "oh, I do this, I do that. Oh, yeah, have you tried..? Ohh, that must be terrible." It is a structured and well researched programme.

**Sophie:** The self management tools that we base all of our courses on are from years of evidence based research, clinically proven and also fed back through patient experience that these tools have helped them better manage. So we've had all of these years we have a handbook that goes alongside our facilitation. And that handbook really, I mean our chronic disease, our long term health condition generic course is now on the 4th edition. So we have grown and we've learned and we've added and we've adapted and new research has gone in, so that we are truly giving up to date and relevant information. And the patients have access to that for the whole six weeks. So in the course sometimes we only cover a small portion of an activity, but then they have further reading should they wish to know more. And that's where then the evidence comes from, they can really delve into the self management tools that they feel are appropriate for them.

**Paul Evans:** And we should say – you said a six week course. So that's one day a week for six weeks?

**Sophie:** Yes, usually on the same day. So our, sort of, model is two and a half hour sessions, six weekly. Although we just have now devised, with clinicians and patients of fibromyalgia, a condition-specific course. And that's eight weeks. And what that does is it looks very specifically in the first two weeks about the condition fibromyalgia and then we move into those six weeks of self management techniques to embed those applied self management tools in relation to that condition. So that is an eight week course, but they are usually six weeks.

**Paul Evans:** And is this just Wales?

**Sophie:** No, Education Programmes for Patients is worldwide! You can access EPP Cymru in Canada, you can access it in America. You can access it everywhere. And the good thing about that is that we follow the quality assurance. So every year all of our tutors are checked, so quality assurance is checked. We're assessed. We're signed off to make sure that the information that we're giving, as you said, is 1) appropriate, 2) up-to-date, 3) correct, and that we as facilitators are doing that well. So it's not just a case of we're taking anybody



and everybody just to talk about self management. We are regularly checked to make sure we're doing justice to the script.

**Paul Evans:** So how do people get onto one?

**Sophie:** It's very easy for us. We have very little criteria. If you're living with or affected by, somebody living with a long term health condition that includes carers. It could even be healthcare professionals that are maybe providing support and maybe their self management isn't perhaps where they would like it to be. You can literally go online to [eppcymru.org](http://eppcymru.org) and within that – it sits within Public Health Wales - you'll see sort of the maps of where you'd like to access the course, but the courses will be the same whether you access them in Aneurin Bevan or Cardiff and Vale.

**Paul Evans:** There's one thing I thought at the time when I did mine. I said no healthcare professionals taking part. I would have liked some healthcare professionals to actually be *subjects*, as in to listen to what is going on there.

**Sophie:** So would I! So would I. And actually the next course that we have running at Cardiff Royal Infirmary, which starts tomorrow. Actually, we do have some occupational therapists going to attend. So we are trying to encourage healthcare professionals to access this as a resource that then, as you've said, if they find it beneficial, they can then use that in their signposting options and also maybe understand what it is we do with the Education Programmes for Patients.

**Paul Evans:** More power to your elbow. Once again, what's the website?

**Sophie:** So it's EPPCymru.org

**Paul Evans:** And Cymru is spelled C-y-m-r-u and it means Wales.

**Sophie:** It does, it does.

**Eluned Morgan:** So I think self management is absolutely crucial. Empowering people to take control, to manage their pain by highlighting supported self management techniques whilst getting professional help when it's needed. And this could include attending persistent pain management programs being supported to learn new skills or attending peer support groups. And I do think that this peer support group approach is something that we really



need to investigate and push in a lot further. Because people going through the same experiences, and they learn from each other in a way that sometimes even professionals can't engage with if they're not going through the same thing. They've got- they've developed their own techniques that they're willing and able to share. And I just think that is a whole new approach that we need to develop the infrastructure for. For these people to meet. Even if it's a digital infrastructure, a virtual infrastructure. I think that powerful knowing it, not going through it alone is really, really transformative for the individual.

*Round Table Discussions Actuality*

**Woman 1:** ...go find your tribe.

**Paul Evans:** Go find your tribe.

**Woman 1:** That needs to be a strap line, I love it! *[laughs]*

**Paul Evans:** Go find your people, go find people that they'll, you know, what you're going through or resonate with them

**Woman 1:** Yeah.

**Paul Evans:** Are things improving? Is there greater support out there, or are things becoming more challenging?

**Woman 1:** Do you want me to answer as the third sector or as an individual? Because I can give you 2 answers. *[laughs]*

**Paul Evans:** Yeah!

**Woman 1:** I think for the third sector, yes, it is improving. We are delivering and doing a lot more. But I think it's that catch-all of getting of what we're doing and what we're delivering and having the capacity to scale it up, as the lovely lady here was saying. I think for me as an individual, no, it's not really changing that much because it's not necessarily being filtered back to me.



**Paul Evans:** And is that because the demand for support is increasing because more and more people..?

**Woman 1:** I think it depends where you live.

**Paul Evans:** So it's still a postcode lottery?

**Woman 1:** Yeah. And we know. And that's a frustration - I think we know there's really great stuff going on over there. But it needs to happen everywhere and that's the challenging piece of it. It comes back again, scale up. Both within the NHS, some within the third sector.

**Mary Cowern:** I'm Mary Cowern. I'm the head of Nation for Cymru Versus Arthritis. I think for third sector organisations it opens up opportunities for us. I think a lot of opportunities to work in partnership and certainly start to give more joined up services for people living in persistent pain. I think we need to break the barriers down. We shouldn't be: third sector – NHS. As there's physiotherapy, occupational therapy. We should be working together as one team for the best thing for that person living with persistent pain to enable them to live well.

**Paul Evans:** One of the things I heard in the discussion was that the third sector organisations are split into specific conditions.

**Mary Cowern:** Mm, yeah.

**Paul Evans:** Would it benefit people with pain if they could work together more?

**Mary Cowern:** I think certainly working together more is the way forward. There are, you're quite right, there's a lot of organizations that are supporting people living in pain, but also supporting people living with specific conditions. And I think by joining it and pooling our resources, because I think there's fantastic knowledge out there, and I think that can only benefit the patient at the end of the day and the person living with pain. It, it's always one of those things, isn't it? Where you tend to lean into your condition, organisation. But when you're working with pain that goes right across such a large spectrum. So I think how we can join it with services, but also how we know what other services are out there that we can refer people in to. Because I'm not able to give you know, do it all within Wales. And I'm sure there are those who are in the same situation. So what can we be supporting other



organisations through sign posting as well and guiding people who come to us over to other organisations who might be able to fill a gap that we're not delivering on. So it is really understanding what each of us is doing and how we can do it together and better.

**Paul Evans:** I think one of the important things about a conference like this is that healthcare professionals who deal with people with persistent pain, they meet people from the third sector, organisations like you. What can they learn from you?

**Mary Cowern:** I think what they can learn from us is actually working differently. We're in the luxury of not having to be so complicated, I think. And you know, the more I hear some of the barriers that the NHS are facing of working in a different way. But we are there to take that broader picture and I think we've got solutions for working in a different way. So, co-producing services and listening to what the patient and the person living with the condition needs as well and how we can respond to that. I think one of the key things that I was hearing today as well, is how we get the message out there as to what the third sector does. Because there's clearly some clinicians in the room that have no idea what we do and what we deliver. So conferences like this are super important. We can be here to showcase what we do, but also have those conversations, right? How can we work together? And it is about working together. It's not about us just doing our stuff in the third sector, it's how we complement and deliver together. Because at the end of the day the person living in the condition just wants to have their pain supported and managed.

**Neil Fowler:** My name is Neil, I'm the clinical lead and inward services lead for Case UK. We are based in Merthyr and we deliver the Access to Work programme across Wales and the South West of England and we also deliver the In-Work Service project across Cardiff, Gwent and the Cwm Taf area across area of South-East Wales. Our company has been going for... six years now, and I suppose fundamentally we're in the business of helping people. And I know that sounds- that always sounds a little bit trite, doesn't it? But that's the kind of ethos and the morals of our company and our culture. What we try and do at all times is put the client, or the participant, or the patient - call it what you will, there are lots of different phrases aren't there - at the forefront of everything that we do.

**Paul Evans:** So what are your clients - patients or whoever - what do they need help with?

**Neil Fowler:** All our participants - which is our preferred term - are in work. We look to ensure that they can maintain that employment. So with support with their physical health



needs, mental health needs, general well-being and general quality of life. Make sure that every day is a good day. And anyone that comes through us, we'd like to think that after they've come through our service, there's none of that - the Sunday Scaries or the not wanting to go into work anymore, you know? I don't think anyone goes to work or anyone is paid enough to go into a job that they that they don't enjoy and then they're not thriving in and we work towards that. And now we we've got a team of physiotherapists, we have counsellors, we have vocational rehabilitation consultants, who are all variously qualified in health related areas. And we work in a bespoke manner, I think, to make sure that people are really well supported and move above and beyond where they are when they first come to us.

**Paul Evans:** So it's mental health, it's physical health, it's well-being.

**Neil Fowler:** It's a one stop well-being shop. *[laughs]* That's what Case UK are, I think.

**Paul Evans:** So these new Welsh pain guidelines being announced today, what do they mean for your clients?

**Neil Fowler:** We focus on quality of life. I think if you compartmentalise, if you like, so to separate physical distress or emotional distress, I think it's very much a false dichotomy. Again, what we look at is people's quality of life and anything that contributes to improved quality of life I think has to be a positive thing for the people that we work for.

**Paul Evans:** Do you have illustrations of people who might have come to you and have been enormously helped?

**Neil Fowler:** There's certainly a rise in people coming to us with fibromyalgia, which often isn't given the credibility that it deserves. But fundamentally, these are people who are reporting they're in pain and they're struggling from a personal perspective. I've worked with a number of participants. And while... you know the status of fibromyalgia, obviously, there isn't anything in the future looking at a cure, but we've been able to look at the research we've been able to look at alternative ways of managing things. We've been able to take what is a physical and neurological condition and work on it from perhaps a cognitive behavioural perspective, which again it ties into what I was saying previously about it's a false dichotomy. You can't separate the two; wellness is wellness, well-being is well-being, quality of life is quality of life. It's a... And I know the term "holistic" does tend to get bandied



around with some of the less evidence based ones, but that holistic approach, that whole person approach, I think that's certainly something that we drive on. And anything like this that seems to be running in the same direction while, you know, Case UK behind it 100%.

**Paul Evans:** Well, I can speak as an expert myself because I have fibromyalgia.

**Neil Fowler:** Oh, okay.

**Paul Evans:** So if I came to you in Case UK, what would the process be?

**Neil Fowler:** So you would come on to one of our services. So for example, if you wish to come onto our Able Futures access to work program, you would be allocated a vocational rehabilitation consultant who would sit down with you - face to face or via Teams, however you prefer it – obviously, change the world. Or, over the phone. And perform sort of a biopsychosocial assessment. And that's a very fancy way of saying I'd speak to you and say, "what's going on, what's happening, what can I help you with?" You know, "what do you need? What do you want me to do?" And we would get a little bit of an action plan together. And a lot of what comes through from people in similar situations to yourself is things... Perhaps my GP isn't taking me as seriously as they might. That's quite common, I've got to be honest with that. Work isn't taking me as seriously as they might, you know. There's a lot of... ignorance, I would imagine. We try and dispel that ignorance, but what we would also help you to realize is that you're not alone in this. So you've got us, you've got me, your vocation rehabilitation consultant. Or we can find you some referral pathways. We can find you some treatment. Through physiotherapy, perhaps through counselling, perhaps through life coaching, perhaps through whatever it is you might find that's missing in your life. Perhaps your employer isn't particularly well aware of the situation. In that case, we can deliver some training. And I suppose from my perspective as a practitioner, as vocation rehabilitation consultant, and what I would be saying to you is: you're not alone, you've got me. But also, have you thought of finding your tribe? Because lots of people don't. Have you thought of finding the people who your condition resonates with, who understand some of the things that you've been through and some of the things that they're going through and give you that different take? I don't know if this resonates with you.

**Paul Evans:** It really does.

**Neil Fowler:** Good.



**Paul Evans:** It sounds like almost a mediator in the middle of everything who *will* listen to you and help you through some of the gates that may be closed.

**Neil Fowler:** Certainly, yeah. Some of the barriers, some of the barriers that are thrown up with any condition. Like from a personal perspective, I'm a migraine sufferer. Everybody knows what a migraine is, but some people say, "Surely... *surely* it's just a headache." Well... well, no. So I could kind of empathise with that frustration and from the perspective of the colleagues that work for us as well. Probably more than 75% of us have experienced similar things to the people that we're working for. And I think that makes a real, real difference when you're trying to support people.

**Paul Evans:** So it's Case UK.

**Neil Fowler:** Case UK Limited.

**Paul Evans:** And the website?

**Neil Fowler:** It's [www.case-uk.co.uk](http://www.case-uk.co.uk) Anyone that needs support can get on the website, give us a ring. We're there to help. I suppose our tagline would be "if what you need is solution, not a waiting list".

**Eluned Morgan:** Communicating without judgment is essential as well, raising awareness that using certain phrases and language to describe the cause of people's pain may be unhelpful or misleading if it's not clearly explained. We often over complicate things, don't we, in relation to health and people come out from surgeries or from healthcare settings, and they haven't got a clue what you've been talking about. And we really need to make sure we simplify our language to make sure that we're communicating in a helpful way.

**Bethany Davies:** My name's Bethany Davies. I'm a healthcare support worker for the pain team at Aneurin Bevan University Health Board. I work alongside Dr. Jeffs with clinics and I also work alongside our chronic pain nurses just offering support and patient liaison, really.

**Paul Evans:** So what does that involve?

**Bethany Davies:** It's the simple things like booking patients in and things like that, but it's also just helping them ease into clinic trying to help with their anxieties that they may have. I act as a chaperone for examinations and things like that. But we've also been working on





some new leaflets, some new patient information leaflets. Including one about sleep and updating our TENS machine information just so it's simpler for our patients to understand. Sometimes I think medical jargon just adds to the stress. So I think if we can make it a little bit easier for them, it does seem to take away some of their anxiety, I've noticed.

**Paul Evans:** Is it rewarding?

**Bethany Davies:** Very, very rewarding. Yeah. You can see a difference in patients just from having a conversation. You can just notice that their anxiety and their stress and their worries seem to just decrease a little bit. And sometimes it's a very emotional job when you hear patient stories and what pain can actually do to somebody. So I used to work in A&E before so I would always see the beginning of the story. But working with the pain team now you see the end and you see what actually persistent pain can do to a person. So I've become very passionate about it.

**Paul Evans:** These Persistent Pain Guidelines, the Wales Persistent Pain Revised Guidelines...

**Bethany Davies:** Yeah

**Paul Evans:** What do you think they'll mean to patients and to you?

**Bethany Davies:** I just think it's just gonna be able to maybe open up a conversation. Just allow that bridge between the patients and clinicians and healthcare. And I think it's just gonna make it a little bit easier to understand *[laughs]* and easier to access the help that they need and that they've been waiting for. Because unfortunately it is a long process. But I like to think that we're now on the step to making things easier for our patients.

**Paul Evans:** And events like this in Cardiff today, they actually bring persistent pain into the limelight.

**Bethany Davies:** Exactly. Yeah, I found working in the pain team that we're not shouting about ourselves enough. And it's something that I'm hoping to bring into our little team and hopefully we can spread that across. But no, I don't think pain is spoken about enough. I don't think it's acknowledged as much as others. So yeah, I think things like this are really important because we need to get that conversation started.



*Round Table Discussions Actuality*

**Man 2:** So what strengths *do* service managers bring to the MDT? *[laughs]* Yeah.

**Woman 2:** And we asked the right questions as well because we're not profession specific. We asked the right questions. I'm, I asked the, you know, not the stupid questions, but the obvious questions. So I think that as well, we ask what needs to be asked. And we – lots of why's, you know, Five Why's.

**Man 2:** But these are probably the same questions that we in Welsh Government and the management at that level want to know. We want to know the holistic view of it rather than, we inject X amount of people per year and everyone seems happy. It's like, well...

**Eluned Morgan:** We also need to reduce ineffective treatments. Now if we follow the principles of prudent and value based healthcare, we *can* reduce ineffective treatments and focus on improving a person's functions. And what's important is that we're helping people with their pain management, but it's not always about the kind of interventions, the medical and pharmaceutical interventions, there are other ways of doing it as well. And not to *over* prescribe is also crucial.

**Catrin:** So my name's Catrin. I'm here from Health Education and Improvement Wales. I'm here with my colleagues from a AWTTC and we're here promoting a resource that we've pulled together with the clinical leads on analgesic stewardship and pain management. It's a resource- web landing page intended for healthcare professionals, so it's got some webinars, links to all the guidance and some useful websites on there that we hope healthcare professionals from across a range of roles and sectors will find useful.

**Paul Evans:** How will the patients benefit from this?

**Catrin:** So they'll benefit indirectly because this is intended for healthcare professional use, obviously by educating and ensuring our healthcare professionals out there have the



accurate information and consistency across the key messages in the guidance, they'll ultimately then be able to benefit their patients.

**Paul Evans:** How do healthcare professionals get in touch with you or get involved in this project?

**Catrin:** So we've been letting healthcare professionals across Wales know about this resource through our networks at Health Education and Improvement Wales, it's been on our social media. But they can find it on the HEIW website under "Support and Awareness Campaigns". There is a page specifically on analgesic stewardship and pain management resources on there.

**Eluned Morgan:** And finally, we need to upskill our workforce by providing advice on continued professional education on persistent pain to ensure we build a multidisciplinary workforce and truly integrated health and social services. So yesterday marked World Patient Safety Day and this year the World Health Organization have chosen the theme "engaging patients for patient safety". The citizen voice is key to ensure our services reflects the needs of those that rely on them.

**Stephen Allen:** My name is Stephen Allen and I'm the regional director for Llais for Cardiff area and Glamorgan. Llais is the new citizens voice body for Wales to replace community health councils prior to april. Our role really is to be the voice of the patient, to be the voice of the citizen, across health and social care services when they're using their services, about their experience. What's important to *them* that they wanna feedback both to local authorities and also the NHS.

**Paul Evans:** So what do these new guidelines, these persistent pain guidelines, mean for your clients?

**Stephen Allen:** I was listening to some of the conversations on one or two tables I could hear and it was very much: the patient doesn't understand what they're being told. The patient doesn't understand what we're saying clinically to them, the patient doesn't understand that well. I would turn that back on and say we're actually... Have you given the opportunity for the patient, 1) to ask you the questions or what you mean, clinically? Secondly, have you said to the patient to go away with this information because there's a consultation - you're only taking about maybe 10% what you hear. You then go away and



think about that. So do you get opportunity for the patient to come back and say, what did you mean by that? What do you mean with that? How often are patients given an opportunity to go back to the person who's giving them whatever news that is? To actually say, "what did you mean by that and what does this mean?" Because only afterwards when you go away, how often we want to see our own GP and the GP can give you some advice. You've gone away, you think "did... did he say to take the blue tablet or the white tablet?" You're not given opportunity to go back and check. So I would say from a persistent pain point of view is how are they going to do a sense check that actually the patients are getting a better service because of this guidance being issued?

We always have to test the NHS, our local authorities. Because the whole ethos of the NHS is patients at the *centre* of the services, but actually for them to be in the centre of the service they need to help to shape and design it and actually assist with bringing it forward and actually being that voice of their community, being the voice within that particular clinical field, bringing that to the table. And I did pick that up from some of the conversations I heard today.

**Paul Evans:** I'm a patient with persistent pain.

**Stephen Allen:** Yeah.

**Paul Evans:** What I feel about coming to a conference like this is... do patients like me actually know that people are talking about them from different disciplines? That they actually- something is being done rather than GP, doctor writing a script.

**Stephen Allen:** I would agree totally because I don't think patients do know. The public don't know this is going on today. I'm quite sure this was opened up to the to the public to volunteer to come in and join. Those with persistent pain or those who have experienced a persistent pain may be careless, for example. It would help them to understand what's actually coming on the line, what they could expect from their clinician when they speak to them. If this guidance is being, sort of, enacted. So those are the things that is having that communication with the wider community, the wider public. To say, actually, we're having a discussion about this. Would you be part of that discussion to help us take it forward and actually make this a living document rather than a document that's put on the shelf somewhere, gathers dust. So what we have to see is it's being lived and enacted in every contact made and not, as you say, the GP just writing a script for sort of a payment. Well,



that's important. Perhaps in some cases we need to live this document. Like any strategy that comes out or any document that comes out, it has to be based on lived experience.

**Eluned Morgan:** I'm pleased to say that along with launching this document, we're working to develop a People's Panel for persistent pain and it's our intention to engage with people who are affected by persistent pain, both directly or indirectly, to make sure their voices are heard and are a part of our future planning.

**Sue Jeffs:** I'm Dr Sue Jeffs, I'm a consultant in pain management, but I'm also one of the national clinical leads for persistent pain in Wales working with Welsh government.

**Paul Evans:** I covered the 2019 document...

**Sue Jeffs:** You did!

**Paul Evans:** And of course as you say COVID has changed everything in the world, but what are the real changes now?

**Sue Jeffs:** I think the real changes is how we talk to our patient group. Where we used to always drag patients to clinic and then them sit in a car and then they get stiff and sore from sitting in the car. We're sort of trying to think more about what's right for the individual. And that's reflected in the document. Again, it's about, where appropriate, doing virtual, telephone, not necessarily bringing patients in. But I also think it's that self management, trying to get that balance between "what can we do as a healthcare support system?" - but also "what can the person with pain do?" And trying to make those two marry a little bit more than they did before. It's that co-production, shared decision making.

**Paul Evans:** So it's bringing the patient into the team.

**Sue Jeffs:** Definitely. They are part of, and they're an expert! They're an expert in their own pain. We forget that sometimes. And so it's about that listening. It's about having the patients know what they want. They felt their pain. They've lived their pain, that pain experience. And that's what we should be working with, is that experience. So yes, you're right, they're part of the MDT team.

**Paul Evans:** So at the end of this Living Well with Persistent Pain in Wales Conference, how confident are you that on Monday morning people will feel brighter about the future?



**Sue Jeffs:** I'm hoping that- we've had so many different people in the room. I'm hoping that will drive discussion. Changes aren't gonna happen overnight, we know that. But I think if we can start those conversations, Owen and I have got lots of ideas and thoughts as to where we want to go moving forward. Some of that's around education, education for healthcare professionals, of all groups, not just the medics, but we're talking about all of the other groups. Working with patients, so we've got our people's panel being developed to try and get that patient voice to understand what *they* want. And what their barriers are to coming to us. But also us perhaps going back to those people living with pain to understand what we can do to support them. So it's that two way conversation. So I'm hoping that in a year's time we will be further down the line. It might not be next week, but we've got lots to work on. To make that difference, hopefully in a year's time.

**Paul Evans:** That's Dr Sue Jeffs, one of the national clinical leads for persistent pain in Wales. As in every edition of Airing Pain I 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 judgements available, you should always consult your health professionals on any matter relating to your health and wellbeing. They are 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, to know what we're doing well or maybe not so well. So do, please, leave your comments or ratings on which ever platform you're listening to this on or the Pain Concern website, which is [painconcern.org.uk](https://painconcern.org.uk). That will help us develop and plan future editions of Airing Pain. And of-course there's more information including links to all the organisations featured in this edition of Airing Pain at the Pain Concern website.

Well, raising the patient voice to delegates at this important Living Well with Persistent Pain in Wales conference was Pain Concern's Heather Wallace. Here are her thoughts on the day before Wales Minister for Health and Social Care, Eluned Morgan's final remarks.

**Heather Wallace:** My impression is it's very, very buzzy. I'm delighted the conference is going ahead. I'm delighted to be asked to present the patient voice. I think we all resonate



with the messages, collaboration, empowerment, helping people function and achieve their potential and their goals, personal choice. But there's a huge challenge at the end of this conference on how we actually roll this out to the benefit of the population in Wales, which is what we must do. But it's a terrific event, great document and I have to congratulate everybody, including the Welsh Government and the Welsh Health Minister for all the work we've put in.

**Eluned Morgan:** My ask of you today is to truly take a person centered approach to working with those who experience persistent pain. To see people not just as patients, but to recognise the whole person behind the symptom, to listen, to have compassion. To communicate clearly and without judgment, and to provide options in place of directives. Please help *us* to help *them* to focus on self management, to improve function rather than just pain relief. To adapt as challenges arise and to engage meaningfully with each individual as the expert in their own life. By working collaboratively, providing holistic care and empowering individuals, their loved ones and their employers, I know we can greatly improve the quality of life of those people living with persistent pain.

Dwi eisiau diolch yn fawr i chi am wrando a gobeithio wnewch chi fwynhau gweddill y diwrnod

I want to thank you for your continued commitment to this cause. You are already transforming people's lives and I do hope that in launching this refresh document, we will be able to go further, we will be able to help more people who are struggling and who need our support.

Diolch yn fawr iawn i chi gyd. [*Translation: Thank you all very much.*] Thank you. [*applause*]

**End**

**Organisations featured and links to website:**

RCS – Real City Strategy: [www.rcswales.co.uk](http://www.rcswales.co.uk)



Education Programmes for Wales: [www.eppcymru.org](http://www.eppcymru.org)

CaseUK: [www.case-uk.co.uk](http://www.case-uk.co.uk)

Versus Arthritis: <https://www.versusarthritis.org/in-your-area/wales/>

Living With Persistent Pain in Wales: <https://www.gov.wales/people-experiencing-persistent-pain-guidance>

**Contact us:**

General enquiries: [info@painconcern.org.uk](mailto:info@painconcern.org.uk)

Media enquiries: [editorial@painconcern.org.uk](mailto:editorial@painconcern.org.uk)

Pain Concern Helpline Telephone: [0300 123 0789](tel:0300 123 0789)

Pain Concern Helpline Email: [help@painconcern.org.uk](mailto:help@painconcern.org.uk)

Office Telephone: 0300 102 0162

© 2010-2023 Pain Concern. All Rights Reserved.

Registered Charity no. SC023559. Company limited by guarantee no. SC546994. 62-66  
Newcraighall Road, Edinburgh EH15 3HS