

## **Airing Pain Programme 52: Better care for people in pain**

### ***How to ensure people in pain get the best treatment: a new guideline for chronic pain in Scotland.***

*At the launch of a new guideline on treatment of chronic pain in Scotland, Paul Evans speaks to patients and healthcare professionals about how to raise awareness and improve care.*

*Marion Beatson and Susan Scott describe the struggles they both endured in trying to get appropriate care after developing chronic pain. They both hope that the new guideline will help people in pain get the support they need in future by setting out clearly the treatment they can expect to receive. Marion's daughter Chloe talks movingly about how her own life and her relationship with her mum have been affected by Marion's chronic pain.*

*Norma Turvill believes the guidelines could raise awareness of the under-recognised issue of chronic pain which is still not understood by some healthcare professionals and Steve Gilbert explains how they could help transform treatment in primary care. Paul Cameron discusses the guideline's advice on exercise and the different ways in which patients can access exercise therapies.*

**Paul Evans:** Hello and welcome to Airing Pain, a programme brought to you by Pain Concern, a UK-based charity working to help, support and inform people living with pain and healthcare professionals. This edition's been funded by a grant from the Scottish Government.

Now, the Scottish Intercollegiate Guidelines Network (SIGN) writes guidelines for people who work in the health service and patients about the best tests and treatments that are available. From 1995 to the start of 2014 136 such guidelines have been written or updated, giving advice on an extensive list of conditions. You can see the full list at the SIGN website, which is [sign.ac.uk](http://sign.ac.uk).

So, number 136, launched just a month ago in December 2013, was on the management of chronic pain. I went along to a packed event in Edinburgh and I spoke to Dr Steve Gilbert, a

pain specialist in Fife, and, for the last 3 years or so, National Lead Clinician on Chronic Pain in Scotland. So, what is SIGN all about?

**Dr Steve Gilbert:** It's an organization that sits within Healthcare Improvement Scotland and brings together people who have a research background, people who've got a clinical background, and also patients and voluntary organisations. And over the last 3 and a bit years we've been involved in looking at all the evidence for pain management, and this guideline is mainly to do with pain management in a non-specialist setting, so that's in the community and primary care. And, as far as I'm aware, it's the first national guideline on the management of chronic pain.

**Paul Evans:** You've obviously been involved in this as Clinical Lead for Pain in Scotland from the very start. How long did it take you?

**Dr Steve Gilbert:** Well, it all started off as a recommendation from the GRIPS report in 2007...

**Paul Evans:** Which was?

**Dr Steve Gilbert:** The GRIPS report was getting integrated with chronic pain services in Scotland, which was the fourth consecutive report into the state of pain services in Scotland. So one of the recommendations was the production of a SIGN guideline.

**Paul Evans:** Reports and guidelines are fantastic things, and they sit in lovely glossy brochures on desks in posh hotels in Edinburgh. How will they be used?

**Dr Steve Gilbert:** Well, I think that's where we've got to take the information that's in the report, and it does show that there's quite a lack of evidence, and there's lots of research that needs to be done. We need to take that out to practitioners in clinics. We've managed to establish service improvement groups, which are people from the specialist pain management services, but also from primary care, and from voluntary organizations with patient representatives and representatives from the boards, so that everybody's got a buy-in to making sure that there's a reliable service model for chronic pain.

And what we've recognized is that only a minority of patients will actually go to a specialist pain clinic, so less than 5% of people who have got a chronic pain problem will be going to see a pain specialist. And, as I often say to GPs, 'I'm a pain specialist. Isn't that dreadful?

Everybody should know something about it!’ And so this is really our mission: it’s to make sure that there’s improvement in knowledge and skills in pain management in the whole level – so in the community, in primary care and in the pain clinics – so that the patient gets the right care when they need it.

**Norma Turvill:** My name’s Norma Turvill. I’m a physiotherapist, and at the moment I have a secondment with Healthcare Improvement Scotland working as a chronic pain facilitator helping the team to roll out the service development for chronic pain.

**Paul Evans:** So what is Healthcare Improvement Scotland?

**Norma Turvill:** Healthcare Improvement Scotland is a team who are tasked with looking after the health of the Scottish population, looking at every aspect of healthcare and identifying the needs, and what needs to be done, and hopefully providing it.

**Paul Evans:** So we’re at the launch of the SIGN guidelines today. What do people with chronic pain in Scotland need?

**Norma Turvill:** Guidance and help, and the profile raised – absolutely. Chronic pain is underrecognised, it’s a big problem for many people, and it isn’t given the same credence as other medical problems like diabetes, epilepsy... It’s a long term condition which many healthcare professionals aren’t aware of, comfortable managing, talking about, so this SIGN guideline today is a perfect way of raising the profile and giving people a platform to work from.

**Marion Beatson:** I’m Marion Beatson, and I’m a patient representative and a volunteer for Pain Concern.

**Paul Evans:** And we’re at the launch of the SIGN guidelines, and you’re speaking to all these professionals about it. What are you going to say?

**Marion Beatson:** I’m going to tell them what happened to me, and what didn’t happen to me, and being concerned with doctors not doing what they should’ve done.

**Paul Evans:** Right, let me start from the beginning. What *did* happen to you?

**Marion Beatson:** I was at work, and the dishwasher was broken, and I went to walk down to the other side of the kitchen, and it had flooded the whole area, and I happened to walk in it and went up into the air and came back down and landed on my back. I finished my shift half an hour earlier, and as I was walking home, it got to the stage that I couldn't walk. That's when it hit me, what I'd done, and what the damage – there must be something wrong.

**Paul Evans:** What didn't happen?

**Marion Beatson:** I never got the right response from my doctor at that time. He just gave me brufen and co-codamol and says, 'everything's ok. It's your back. Give it 6 to 8 weeks, and you'll be fine.' After 6 weeks he sent me back to work. When I said, 'no, something is wrong', but he didn't listen to me, and I ended up taking more medication than I should've to help cope with the pain. And it took a year of me trying to work, but I couldn't. So I ended up going on a sick.

And after a year I moved home. And it wasn't till I went to my original doctor's when I was growing up that he took me off everything and told me that I was overdosing and that I could've easily have not woke up again. So that scared me; that frightened me. And it was then that I started the process of getting information and seeing the right doctors and finding out what was wrong with me.

**Paul Evans:** Do you blame the medical profession that was dealing with you?

**Marion Beatson:** I did.

**Paul Evans:** Do you now?

**Marion Beatson:** No.

**Paul Evans:** Why?

**Marion Beatson:** I was angry for many, many years of what had happened to me, and – why me? But it took patience from the doctors and psychologists and all the nurses and everybody that helped me to realise: 'It's happened, there's nothing I can do about it, and I have to accept it'.

And accepting what is wrong with you is one of the hardest things to do because you want answers. I couldn't get answers because I had no definition of what was wrong with me. Nothing showed up on X-rays or MRIs, so it was just a case of 'injured back'.

But it wasn't till I had seen a neurologist that he told me about the nerve damage that I'd sustained, and that is why down my left side is not fully functioning properly. The nerves are not getting the right sensations. So because I had learned what was wrong, I accepted it a wee bit more and that was the start of the process of learning to get on with it.

**Paul Evans:** When you speak to these doctors and health professionals and health administrators today, do you think they'll be surprised with your story?

**Marion Beatson:** Yes, because a lot of them are, as in 'I don't want to hear what is going on'. They want to help, the information's there for them to do it, but all it takes is getting to know somebody with pain to make them realise: 'Hold on a minute, right, now the process has to start of me learning what to do and how to recognise it.'

**Paul Evans:** You've brought Chloe, your daughter, and David, your husband, along with you. Why have you done that?

**Marion Beatson:** Because I want them involved in what is wrong – going on with me, and for them to learn that it's affected them as much as it's affected me. They've got a right to say how it's affected them.

**Paul Evans:** Are they aware that it's affected them?

**Marion Beatson:** My husband isn't. My daughter is, yes.

**Paul Evans:** Why not your husband?

**Marion Beatson:** He sees it as being, as long as I'm alright, he's ok.

**Paul Evans:** You're all in this together.

**Marion Beatson:** Yeah. He's my carer, but he's not classed, as in, legally, as my carer.

**Paul Evans:** And Chloe, she's 14?

**Marion Beatson:** She's 14, yes.

**Paul Evans:** Is *she* your carer?

**Marion Beatson:** I try not to class her as that, because I don't want her to be classed as a carer.

**Paul Evans:** But is she?

**Marion Beatson:** She says she is, but I keep saying she needs to do more housework.  
(laughs)

**Paul Evans:** But that's just mums and 14-year-olds...

**Marion Beatson:** Yes, that's mums and 14-year-olds, yes, yes. She actually does look after me, yes. She's very thoughtful when it comes to things – and plus she is – she was 2 years old when I had my accident. So, she hasn't known me any other way. And when other people talk about me as in being the 'old Marion', the one that was fun-loving and dancing all the time, and never in, it's a case of 'you don't know – your mum used to do this, your mum used to do that', and she gives it, 'well, I don't know'. She is hearing another side of me but she's never *seen* that side of me. And she can't imagine it.

**Paul Evans:** She sees the mums of her friends...

**Marion Beatson:** Yeah.

**Paul Evans:** ...who *can* do these things...

**Marion Beatson:** Yeah, she really notices that. That upsets me more than anything else. It's because I can't do what they do. And she accepts it. She's like 'It's ok, mum. I don't need that; I don't need to do that.'

But there is a time that I would love to say, 'somebody's gonna come pick her up', and just take her. I actually went to a JLS concert with her one Saturday night, and it was for her birthday, and I say 'take anyone you want to', and she says, 'mum, I want you to come with me.' And I had a ball! I loved every minute of it. And she... because I was there and I was

integrating with her, she just went in a wee world of her own. It was wonderful to see. It was the happiest I've seen her in a long, long time. So I enjoyed it because it made her happy.

**Paul Evans:** Marion Beatson. And we'll get Chloe's response after mum has addressed those at this launch. But here is Dr Lesley Colvin. She's a pain consultant and chaired the development group for these SIGN guidelines.

**Dr Lesley Colvin:** To give you a little bit of the history of why we're here, when this chronic pain steering group was first set up by Pete Mackenzie, oh, 7 or 8 years ago, one of the aims of that was to make sure that services nationally were providing equitable access to good chronic pain services. As part of that, there was a recognition that we actually weren't quite sure what good chronic pain services consisted of, and what we should be providing, because, there was no good overall review of the current evidence.

There was a huge amount of literature out there, and it's going through and it was assessing what the quality is, and producing a guideline using the very strict SIGN methodology which is internationally recognised as producing quality guidelines. And I think that will be very useful for all health boards. And I think we're in a unique position that we're not... haven't just produced the SIGN guideline, it's number 136, there's lots of SIGN guidelines, but we've also produced it at the same time that every health board in Scotland has central funding to set up the service improvement group. And there's a huge amount of enthusiasm from the healthcare professionals involved in chronic pain services to improve the service and provide the best practice in their local area.

However, having said that, you know, if you don't know what best practice is, it's difficult to do it, so I think the SIGN guideline will help to underpin that. And looking at the key recommendations and breaking it down into delivering those key recommendations at health board level through the service improvement groups should help to move a step towards, perhaps not perfection, but certainly a step towards providing good quality care throughout Scotland in all the health boards, regardless of where you happen to live.

**Dr Steve Gilbert:** Patients have been brought in to help and to design this service model, so that's mainly been, in this service improvement group, trying to recruit somebody who's been in the specialist pain service and has some experience of pain management approach. But we've also had a lot of assistance from yourselves in Pain Concern and Pain Association Scotland, so voluntary organisations have obviously got a lot of fair patient user involvement.

And in Scotland, we've got the Alliance which is a coalition of the voluntary organisations in Scotland, and that's been really helpful in getting the patient voice in there.

**Paul Evans:** In what way?

**Dr Steve Gilbert:** When we're working in pain management, we can be very focused on trying to get more services, so we want more time to see our patients, we want more staff in the clinics, and we want proper funding, and so on. And what we've realised, in fact, is that to manage most people's pain, what we need is just the right knowledge and advice.

If we just took it from a service pain specialist point of view, we would have lovely shiny clinics with only a few people coming to see us, and the majority of people would still be wandering around with their chronic pain, not knowing what to do.

**Susan Scott:** My name's Susan Scott. I suffer from chronic pain and I have done for 18 years, but I also – in my other life, I'm a community dental officer, working in Cumbernauld, part-time now.

**Paul Evans:** Now, you were addressing the launch of the SIGN guidelines in Edinburgh today. What were you telling them?

**Susan Scott:** I was telling them about my story, which started 18 years ago, what happened and what my experiences have been in the NHS with the pain service. Eighteen years ago it was quite difficult, because there wasn't a lot of pain services in Scotland. I had an operation on my spine, which was successful, but left me in pain, and you were just left to get on with it.

It was about 5 years before I found out about a pain management programme, and it just was by chance. It was the year 2000, I was having a bad flare-up, and my brother-in-law looked online to find out if he could do something to help me, and he spoke to a man online from down South who mentioned pain management programmes, and mentioned there was one in Scotland, in the Astley Ainslie in Edinburgh. We got the details, and I took it to my GP. He didn't even know anything about the course, but he quite happily referred me.

And I went to the course, learned about pain management techniques, pacing, goal setting, relaxation, met a lot of people in similar circumstances, and that sort of changed my outlook



of the whole thing, and improved my life greatly, and really has made me stay as active and stayed at work as I possibly can.

**Paul Evans:** Did you have to give up work at one point?

**Susan Scott:** I did. When I first prolapsed my disc, I was working for a health board as a dentist, working with children in special needs. And I had to give up clinical dentistry for two years.

Luckily, my bosses in NHS Lanarkshire have been absolutely brilliant to me. And after I had my operation, it was about a year since I had been off work. They couldn't give me my dental job back. But one of the doctors at the hospital suggested to them: 'could they keep me on in some other way?'

So for a year I did dental health education: going to schools and talking to pupils in primary schools, which was quite daunting: I was used to talking one-to-one. When you're facing a class full of primary sevens, I didn't know what terminology to speak to – so I learned quite a few new skills.

And I did that for a year, and after that the neurosurgeon okayed it for me to try clinical dentistry, my work allowed me to try and very kindly found a couple of half-day sessions for me to start with, and then I got back into dentistry that way.

**Paul Evans:** So this is good employers valuing you and finding a way of getting you back to work.

**Susan Scott:** Yes.

**Paul Evans:** Susan Scott.

Paul Cameron is the clinical lead specialist physiotherapist for the pain service in Fife. He's also a researcher at the medical research unit at Dundee University and, as one of the members of the SIGN guideline development group, he looked specifically at the relevance of physical therapies in the management of chronic pain.

**Paul Cameron:** The question was looking at whether physical therapies were recommended or useful in the treatment of chronic pain, and what type of physical therapies there were,

and did they give up to 50% pain relief. And the answer was largely yes, that they did help, particularly exercise, use of some manual therapies in certain circumstances.

Looking at the evidence of course, it's like anything with guidelines: we have to stick to a certain level of evidence and one of the things that was recognised I think throughout the guidelines was that a lot of work has been done, but often doesn't quite reach the standard of scientific evidence that's required to get into a guideline. So as other key questions found, there was evidence found, we were able to make some recommendations, but also recognised that some work still needs to be done.

**Paul Evans:** But you're a physio, did you really need the academic proof that physical activity is good for people with chronic pain?

**Paul Cameron:** I think, like anyone who's a clinician in any area, you have got instincts, but sometimes, particularly in a world now where evidence-based medicine is really the driver for many services, it's important to do that work, not only to find out what evidence is available, but also to find out what evidence *isn't* available, and equally to make sure that research and work is done into those areas.

So yes, as a physiotherapist, I'm obviously thinking, of course, physical activity is useful, but, as an academic, I'd like to see the evidence for that a bit more robustly. And the physical therapies section wasn't about physiotherapy, which is a profession, it was about physical therapies, and it's not just physiotherapists who deliver that.

**Paul Evans:** Who else delivers it?

**Paul Cameron:** Well, a number of professionals: exercise therapists, sports therapists... I mean, when you're talking about a guideline with a recommendation about exercise, that would include going down to your local gym. And part of it is around the evidence as what type of exercise, but equally it's about encouraging those clinicians that are going to be using these guidelines to encourage their patients.

**Paul Evans:** I mean, certainly where I come from in South Wales, I was prescribed, if you like, exercise in my local authority leisure centre. I had a personal trainer, and I could go to the gym for 6 months. I would have loved to have been supervised by a physio, but is that the sort of thing you're talking about?

**Paul Cameron:** It's a bit of a mixture. When you look at the span of chronic pain and patients who have chronic pain, you have those that can manage quite well actually without any professional help, equally you'll have those at the other end of the spectrum that need quite a lot of help, and when I say help, I mean actual support. A lot of the time there's people that are scared as to what might happen when they carry on exercise, and in many cases the physiotherapist's role is to, as you say, prescribe exercises that are a little bit more specific. And that might be taking it to count other comorbidities and other problems that patients may have.

But equally for those patients at the end of the spectrum where they can manage quite well, those people are encouraged to do more exercise in their local health centre. Where the difficulties may lie are the exercise therapists or the gym instructors being wary themselves about giving the wrong exercise and that... I hope that some of these guidelines will help with that as well.

**Paul Evans:** How will you get it into their hands, do you think?

**Paul Cameron:** Obviously, dissemination, it's one of these things that it requires a lot of people to be involved. Today is a good example of that. If you look at the list of the delegates at the event, it's not just clinicians, it's also patients, it's patient interest groups, it's charities, like yourselves, and we're hoping that everybody is involved in passing these guidelines out.

**Paul Evans:** Paul Cameron.

There are full details of the SIGN guidelines for the management of chronic pain at the website [sign.ac.uk](http://sign.ac.uk). But also launched at this event was a new website at [chronicpainscotland.org](http://chronicpainscotland.org), that's one word, chronicpainscotland.org. And that's a central resource for people with pain, service user groups, and for other healthcare professionals not directly associated with the management of pain. Both sites are a mine of information, not just for people living in Scotland, but for everyone associated with the pain community wherever you are.

Pain Concern's usual small print is that whilst we believe the information and opinions on **Airing Pain** are accurate and sound, based on the best judgements available, you should always consult *your* health professional on any matter relating to your health and wellbeing: he or she is the only person who knows you and your circumstances and therefore the appropriate action to take on your behalf.

Now don't forget that you can still download all 52 editions of ***Airing Pain*** from [painconcern.org.uk](http://painconcern.org.uk) or you can obtain CD copies direct from Pain Concern. Please do visit the website, where you can find all sorts of essential information about pain management, including details of ***Pain Matters***, our magazine that complements and expands on issues covered in ***Airing Pain***. As well as in paper form, ***Pain Matters*** is now available as a digital download. For those who use media on computers, tablets, smartphones, the digital editions are not only a more convenient way of receiving your copy of ***Pain Matters***, but they also offer an enhanced user experience with links to audio and other relevant information. So please, do check it out at the Pain Concern website: once again, it's [painconcern.org.uk](http://painconcern.org.uk).

Now, earlier we heard from Marion Beatson who's lived with chronic pain for many years as she was about to address the delegates at the launch of the SIGN guidelines for the management of chronic pain. And I promised I would get 14-year-old daughter Chloe's response.

Chloe...

**Chloe Beatson:** Hello.

**Paul Evans:** We've just heard mum speak. What did you think?

**Chloe Beatson:** I thought she was absolutely fantastic.

**Paul Evans:** What was the best thing she said?

**Chloe Beatson:** The bit where she said I used to run my finger down her back and set her nerve's off, 'cause that's very true.

**Paul Evans:** So, how do you help her?

**Chloe Beatson:** Well if she's sore, I'll sometimes rub her back. If not, I'll try and do anything to help her, like I'll make her a cup of coffee or whatever.

**Paul Evans:** Do you do the housework for her?

**Chloe Beatson:** Sometimes.

**Paul Evans:** But you just told me you don't clean your room!

**Chloe Beatson:** My room's normally tidy, but it's more, I do the Hoovering, and sometimes I do the dishes.

**Paul Evans:** So do you think you're one of mum's carers?

**Chloe Beatson:** I'd say my dad's more my mum's carer, but I still help, 'cause I'm still having to try and go through school as well, and it's being young and still having a life, if you know what I mean. But, no, I still like to help my mum, because if I don't help her, I know she's in much more pain which makes me feel worried whenever I see her.

When I was really young – like, I understand now that I'm older – but I used to look at my friends, and they'd all be going on holidays with, like, the rock climbing and the cycling and big pools, and I've never been able to experience that because my mum's in pain. And I understand now why not, but it still doesn't take away the fact of, I'd still like to do it. Even though I can't do it, though there's some other things we can do, but it's not as good with my age, if you know what I mean. It's kinda more my mum and dad, but I still love her.

**Paul Evans:** I can tell that. You went to see JLS last Saturday, didn't you?

**Chloe Beatson:** Yes, how did you tell? (laughs)

**Paul Evans:** And you took your mum.

**Chloe Beatson:** Uh-huh.

**Paul Evans:** I know when I was 14, I...

**Chloe Beatson:** It was uncool.

**Paul Evans:** Uncool didn't come into it. If I played, then they wanted to come... mum said she had an absolute ball of it.

**Chloe Beatson:** Uh-huh. We had a great time. We had to get moved seats, because there were so many stairs, but the people in the Hydro were very nice and moved us down to the disabled bit, and my mum had a chair if she needed it, and we had the whole floor to ourselves, had an absolute ball.

**Paul Evans:** You obviously feel very comfortable with mum.

**Chloe Beatson:** Uh-huh. I wouldn't be able to cope without her.

**Paul Evans:** Do you think you have such a good relationship with mum *because* of her pain?

**Chloe Beatson:** I think so, 'cause if she didn't have her pain, she'd be at work. But now that my mum's in, if I'd had a bad day at school, I've got someone there right away, I can tell my mum all my problems and stuff. But I worry whenever she takes a flare-up or something, because I don't know how she feels, it's kinda scary now when I see her.

**Paul Evans:** And when was the last time she had a flare-up?

**Chloe Beatson:** About 2-3 weeks ago.

**Paul Evans:** What did it look like to you?

**Chloe Beatson:** It was like she was taking spasms, but now I understand where it's coming from, and the fact of, she just can't stop it. It makes you feel as if, why can't I take some of that away? But she has to live with it and she deals with it quite well.

**Paul Evans:** She is a very impressive lady.

**Chloe Beatson:** Yes.

**Paul Evans:** With all the educational stuff, and spreading the good message about proper pain management, are you proud of her?

**Chloe Beatson:** I'm very proud of her. She's out of the house, like, a lot now. I don't see her much, but I'm very proud of her when I hear that she's on the radio, or she's like – today, she's done her speech, and I've had the opportunity to see her, and she's just made me so proud.

**Paul Evans:** Now, I know that she asked you to write something about what the pain means to you, and what your relationship with mum's pain is. What did you say?

**Chloe Beatson:** I kinda said stuff like, when I was young, I never understood, but seeing her now, I know that it's made her a better person, and I don't know what life would be like without my mum having the pain. I know it sounds kinda cruel, but I think life would be completely different, and I'm starting to get to grips with the fact that my mum's got this 'till the day she dies. And I hope to be there with her to help her through it.

**Paul Evans:** Do you think it's made you a better person?

**Chloe Beatson:** Yes, as I've got older. Like, all my other friends get whatever they want from their mums, or their mums will take them wherever, but with my mum, I just go out on a walk with her. Makes me feel as if I've got more time with her, makes me feel special. Like, the JLS concert was the best night I've had in years, and to be able to spend that with my mum's fantastic.

I think I see things a bit better, if you know what I mean, like, the bright side of things, 'cause I've always been told I'm an optimistic one, because whenever I see my mum, and I see that she's having, like, a bad day, I'll try whatever to make her day better. So whenever one of my friends are having a bad day, I'll do whatever I can to try and cheer them up or cheer them on for whatever they've got, 'cause it's not fair, if you feel bad, you need to have an optimistic mind to make the day better.

**Paul Evans:** What's the best thing about mum?

**Chloe Beatson:** That I can tell her everything. She's, like, my wee person that I throw everything upon. And she'll always make me feel better and give me a cuddle when I need it.

**Paul Evans:** That's Chloe Beatson. Later in the year, Pain Concern will be running a campaign of support for young adult carers like Chloe. But the last words from this launch of the SIGN guidelines for the management of chronic pain go to mum, Marion. Will the guidelines change things for the better?

**Marion Beatson:** I hope so, maybe not right away. It is going to take time. But we have to look to the future and the people that we can help in the future, starting now. And the more information we have and we pass on to them, especially patients, patients have to be involved, because we are the ones that know exactly what is going on with their bodies, in their minds, and everything else. And if we all work together, hopefully, cross fingers, people

will get the help that they need, and they won't have the long-term psychological damage that it can do to a person.

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