

Airing Pain 113: Translating Chronic Pain

Using creative writing to better represent the chronic pain experience

*This edition of **Airing Pain** has been funded by the Arts and Humanities Research Council.*

Chronic pain often exists in ways that cannot be seen. Due to the intangible and ambiguous nature of many chronic pain conditions that lack clear-cut causes and treatment, patients feel frustrated when communicating with healthcare professionals, personal networks, and the public at large; they feel 'invisible'. Lancaster University's English and Creative Writing department has built a research network to collect short-form 'flash' illness writing; pieces that aim to better represent people's experiences of chronic pain.

*In this edition of **Airing Pain** we hear from the project's Principal Investigator Dr Sara Wasson about the many components that make up the project, its origins, and the goal of conveying the experience that millions of people go through every day.*

Issues covered in this programme include: Arts and crafts, communicating pain, creative project, creative writing, culture, describing pain, educating healthcare professionals, explaining pain, inequality, intersectionality, misconceptions, muscle spasms, personal experience, poetry, representation of pain, spasmodic torticollis, stigma, visibility and writing.

Paul Evans: This is **Airing Pain**, the programme brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain and for health care professionals. And this edition of **Airing Pain** has been funded by the Arts and Humanities Research Council.

Multiple speakers: *I want my mom. I want my mom. I want my mom... and Pain that just backs off for a while. The difference between the morning pills and the afternoon pills and the evening pills and the night pills and the pills and the pills and the injections and the appointments and the Pain... I want my mom... A rookery, long abandoned now, had been built inside my body. I don't know where the birds went or why. One day, they uninhabited, leaving only their barbed-wire residues, strung across the boughs of my hips... I want mom. I want my mom... This deep, stabbing pain in both temples. The buzzing flight of sugar-fuelled hummingbirds. The way my entire body is filled with pain and unable to move from this chair... I want my mom. I want my mom...*

Evans: In the previous edition of *Airing Pain*, we talked about how pain is measured; measured, that is, by scientists. As patients, however, whilst doctors may be able to assess our pain, rarely I suspect do we have the ability to communicate our private and deepest feelings about living with pain at any one given moment. As Pain Concern's own 'Breaking Barriers' research project illustrated only too well, people living with chronic pain repeatedly report being marginalised and stigmatised by health care professionals, their personal networks, and the wider public. This invisibility, according to researchers at Lancaster University, is partly because chronic pain can be hard to turn into a story because of its unpredictability and resistance to clear cause and cure. So, rather than offering life story narratives to make sense of living with chronic pain, the university's 'Translating Chronic Pain' Critical Creative Project focuses on representing fragments or moments of chronic pain experience through what they call 'flash' illness writing.

Sarah Wasson is a lecturer at the English Department in Lancaster University. She's leader of the 'Translating Chronic Pain' project.

Sarah Wasson: Well, the project is really quite broad and has many components to it. But the bit that I'm going to talk about now is the creative project. And in that there are two particular sections, [but] the most significant [has] been the online anthology. We've asked people around the world to write short fragments of between five and 150 words that respond to or capture something about the experience of living with pain, or caring for others with pain, or working through some aspect of pain experience in the broader sense. So it's a very broad call. The call for work was... we made it into a poem, after a collaborative project with pain charities and others. I felt very strongly that, if we were going to do a project like this, the goals of the project had to be specified and conformed collaboratively right at the beginning among many of us living with pain, pain charity representatives, medics, and academics. And it's very important to me that, the whole way through, the project has not been about academics in one box, and people living with pain in another. Almost all the academics involved have either lived with pain themselves, or care for others who do. So there's a lot of overlap between the creators and the academics and the people in pain. Many people are all three. We brought lots of people together and explored what short writing form might do; how it might be good, how it might be dangerous, what might be promising, and the perils of it, too. After that, I wrote the poem, which is kind of a call to arms – a manifesto. Shall I read it?

Evans: Yes, please.

Wasson: 'Call for Creative Work: Creative Manifesto – Translating Chronic Pain':

SINCE people living with persistent pain often suffer **invisibility** and struggle for **legitimacy** and credibility;
since long term pain is often assumed to be a **temporary and unnatural** state;
since pain experience is **diverse** and must be understood **intersectionally** (through interweaved categories such as gender, race, sexuality, and class);
since pain's **causes** can be cryptic, multiple, personal, social, environmental, transgenerational, and hidden;
since pain **science** is neither widely understood nor well-funded, and requires wider dissemination;
since pain experience **exceeds the language** of medicalisation;
since pain **undercuts illusions of human autonomy** and self-sufficiency, showing all people are **vulnerable and interdependent**;
since pain may impair the ability to **work**, in which case those living it may be seen wrongly as not living a 'useful' life;
since **witnessing pain** makes profound claims on – and poses challenges for – carers, family members, and healthcare practitioners;
and since chronic pain affects **every dimension** of life...

...I call for creative work that engages these invisibilities, these lacunae, these intersections – moments in public or in shadows, in loneliness or connection. YET - pain experience may not lend itself to established forms of either illness narration or survivorship story:

the experience may lack an **ending** where resolution is reached;
it may lack a **beginning**, its causes hidden;
it may break the **positivity imperative** – to be hopeful, a warrior, a survivor, a meaning finder;
it may be **incommunicable**, resisting representation, yet may simultaneously **engender language**;
it may be a story not (only) of a personal journey, but of wider **social** calamities and inequalities:
and it may **resist plot**, instead being a thing of **fragments, glimpses, and moments**.

Evans: This is the first time we've met. I don't think that somebody who wrote that would not have experienced chronic pain.

Wasson: [laughs softly] Well, I can't take full credit for writing it because it was... it emerged from the creative summit. But yes, I definitely do live with pain myself. I've got about – I think, at the last count – eight different ways in which... conditions [in] which that is part of it. I don't generally share that as the first thing in the project, though, because I felt very strongly right from the beginning that I don't want to limit the pain story or in any way set myself up as an authority. So I tend to be in the background with that.

Evans: It's very interesting; you were talking about storytelling involving chronic pain. I can't think of many great stories in popular fiction or television dramas, in fact, that feature chronic pain.

Wasson: I was thinking about this this morning, actually, when I was looking again at Virginia Woolf's famous and amazing essay on being ill. And there's that extraordinary line there, where she talks about how, when it comes to describing a headache, there isn't really a long lineage of literary representation. And instead, what she says she wants to do is to grab the pain in one hand, and a lump of sound in the other, and squash them together to create something primitive, sensual, and obscene, which is an extraordinary kind of call for innovation. And there are many ways in which poets – and I'm thinking again of Emily Dickinson, in particular, actually – have tried to bend language in the way Virginia Woolf called for, but there's still more to be done because there is something so subjective and elusive about that experience. And to get it to be taken seriously.

One of the things that probably drove me to do this – bring all these different activities together – [was] profound sadness at how much social science research has shown people living with pain feel invisible. And the word 'delegitimate' gets used a lot somehow – not rendered valid. And this came out through so much research, across all different countries I was looking at, and it's a *tiny* response to that, I guess. It's a way of trying to find ways of vividly communicating in short form. Also for hearers, to try and help [to make] the reality of that experience more available to people who perhaps don't have that experience. It's to try and help people on all parts of the continuum. That's the hope.

Evans: Holly Hirst is a PhD associate lecturer. She has chronic pain and contributed to the 'Translating Chronic Pain' project.

Holly Hirst: I wrote two pieces about, sort of, different aspects of living with pain. One was about sort of the spiritual aspect, and one was about communication, I guess. So, one that I wrote was 'The Exorcism of Spasmodic Torticollis', which is what I have.

Evans: Spasmodic Torticollis... What is that?

Hirst: It's an inherited neurological condition, which is one of the dystonias. It means that I can't control the muscles in my neck frequently, and so that they spasm, causing pain, and that has... It can also spread through the body, so my arm and shoulder and top of my back are also spasmodic. So:

'This is my best exorcist impression,' I tell you with a grimacing grin.

I tell you it's a horror movie to make you laugh. So that you can laugh at the girl controlled by demons. As her head turns full circle on her neck. As her smile screams with silent blasphemy. Because if you don't laugh, you turn away. You'll never follow Karras through the window. You'll turn and walk downstairs, sit with Chris and hope it goes away.

Evans: The other fragment is 'Doubt There Is No God'.

Hurst: So:

There is no God. I know it. I feel it in this agony. This violence. As my brain tricks my body into ripping itself apart. There isn't. There can't be. Please God. There can't be.

One of the things that I really appreciated about this project is the ability to convey a moment, rather than to convey a narrative. And this idea that this could be a moment of thought, of experience that you have – that it doesn't have to be a summary of your whole story. But those moments of desperation when, you know, you wake up in the middle of the night, and your body's screaming, and there's nothing you can do about it. When you're trying to achieve something that you simply can't achieve because your body won't obey you. When you've been spasming for a couple of hours, and you can't do anything about it, and people tell you things like, 'Well, it's all in God's plan,' or...

Evans: 'I know how you feel.'

Hurst: 'I know how you feel.' And what your brain tells you – what your body *feels* – is that that cannot be true. Because this is so horrendous. When people say things like, you know, 'The creation of the body is a wonderful thing,' I don't know what went wrong with mine. [laughs] So it's that kind of experience, that kind of moment, without trying to put it within the context of humour, or telling a story about my whole, sort of, journey of faith. But just that moment that's very real, I think, when you're in it.

Evans: The fragment of time, the moment... We're not talking about 'This is my illness; this is how it affects me from day to day.' It's my thought, at a certain time.

Hurst: Yes, one of the pieces that moved me most: one simple phrase repeated multiple times. And that spoke to me a great deal because that is the experience that you have. I mean, I don't know about everyone else, but my brain skips when I'm in pain. So I can't think – I get stuck. It's like my brain stutters, and that thought will just come again and again and again.

Unknown speaker: 'I Want My Mom' by Socks.

i want my mom i want
my mom i want my mom i want my mom i want my mom i want my mom i want my
mom i want my mom i want my mom...

Evans: Those feelings... I think many people with chronic pain have actually felt that. You know, we know all the management techniques – this, that, the other – but there are times when you just think 'I hate this.'

Wasson: Yeah... This is something that I was so grateful to see happen. I didn't know what kind of range of work we would get, but the emotional range has been colossal. So there have been works of a hopeful moment, and which we all have also. But somehow the fact that it was a moment or glimpse meant people were freed from the compulsory optimism of the long story, which is a bit of a fierce way of putting it. People living with pain do have to internalise certain kinds of management strategies that do tend to orient more towards the hopeful. But this kind of seemed to give a safer space where people could explore a range of emotions, which weren't always totally just upbeat – they were a range. One of the poems that came early in, and I would love to read, was Roseanne Watt's 'The Diagnosis'. I thought this was such an extraordinary work because it captures that suspense and fear that can attend on a diagnosis [while], of course, on the other hand, many people living with pain do not get one – do not get a diagnosis – and really would like one to be taken seriously, as well. So, this is what Roseanne wrote about with 'Diagnosis':

A rookery, long abandoned now,
had been built inside my body.

I don't know where the birds went
or why, one day, they uninhabited,

leaving only their barbed-wire
residues, strung across the boughs

of my hips; all sticks and spit,

all hollows meant for holding

something small, still desperately
alive. I'm sorry – I'm afraid

I know only my own dark canopy,
its filtering bones of light

Evans: It's very, very... moving, and obviously very, very personal. I don't know what condition Roseanne lives with, but there is a common sort of feeling. I thought when I found out about this, 'Well, I'm going to write something myself.' I couldn't do it.

Wasson: [gasps in astonishment]

Evans: Because it was almost like, learning to live with a condition, you are conditioned to that condition, and I don't want to step off that condition, and let my barriers down, if you like.

Wasson: Yeah... Very interesting.

Evans: Because a lot of these are pretty dark.

Wasson: Something that's been very striking in the way that people have responded to the project, the email and the feedback that we've had, which has been very moving, has been relief at the validation of those moments, actually – of the not feeling alone, and the waking at 3am, as you said, Holly, you know. Without saying that despair is the only way in, I think it sometimes is part of the moments and fragments. And I guess if part of that's what this anthology is showing, then I'm glad.

Unknown speaker: 'pain and Pain' by M-S-Y from the United States.

The difference between lowercase-p, pain, and uppercase-P, Pain, is huge.

Bigger than just a shift-key should make it.

The difference between 'Yeah, let's go on a hike today!' and 'I can't walk today.'

The difference between pain that ends, and *Pain* that just backs off for a while.

The difference between the morning pills and the afternoon pills and the evening pills and the night pills and the pills and the pills and the injections and the appointments and the *Pain*.

The differences between the screaming in your head and the screaming locked in the gilded cage in your throat, and the knowledge that it is a bird that will never die, it will just remain in you, like a bird throwing itself against a window pane. Yes, pain and *Pain* are so completely different, I can't believe they're even spelled that same way.

Evans: Ones that I found rather moving, and / think – perhaps I'm wrong here – it's about relationships, it's about loneliness...

Wasson: Yes, this beautiful fragment by Lucy Goodwill:

She is struggling with the concept of her body as a sensual object. She lifts the covers, brings her feet to meet the floor and winces as she stands. Legs laced with his now buckle as she walks, and shockwaves sparked by his touch are replaced by short-circuiting pain in her nerves.

Soft lips, coarse hair, hot skin, cool sweat, forget the pain, leave that 'til morning. She makes it to the door; tries not to wake him so he won't see her transformation. From time to time she indulges in the mythology of her beauty; an existence where physicality means something other than her suffering.

She pours the coffee that will focus her, swallows tablets that will soothe, takes a shower and embraces the heat that reaches deep into her bones. She follows the steps that will make her feel human and, symptom by symptom, she rebuilds the myth.

Evans: It's written in the third person, but I'm assuming it is that she is the person. To me it appears it's somebody looking in a mirror at somebody who's not there.

Wasson: The extraordinary thing that strikes me through a lot of the writing in the project, and indeed in a lot of the other writing around chronic pain in memoirs, is the strange play of absence and presence to the self. The ways in which, in some ways, one's experience becomes so... almost overwhelmingly alien, and one's body becomes deeply estranged sometimes. And I think that the third person captures it so well. [Also], what I love so much about this poem also is it shows how pain affects subtle, intimate parts of life. And, in this case – both her romantic and sexual relationship – it's of the persona and the speaker, but also the sense of one's own appearance, and the labours – the everyday, ordinary labours that everyone does... kind of, you know, hygiene – that become much more complicated and interesting. And the myth of her beauty, the mythology of her beauty, is something that's presented as achieved with *extra* labour effort. It's almost a lie, yet a lie that she's invested in.

Unknown speaker: 'Food for Thought' by Ryan Michael Dumas.

Just got a letter from disability insurance: Denied. I'm not *disabled enough* to get anything. After months of trying to convince them.

How do you prove you can't work?

I cannot sit up, stand, or walk hardly at all. There is no job I can do while laying down, without having to make phone calls.

Just laying here, my back aches. But it's the most comfortable position I can find. (It hurts my hips but those aren't important.)

If I dared to sit up, my lower and upper back would scream in agony. It would not end until I laid back down.

I couldn't keep working; had to move back in with my toxic parents. I have no money, no freedom, and no chance. I have no future. And that terrifies me.

I'm a survivor. The world wants me dead. It's only a matter of time.

Evans: The creative arts have been used as a way of managing pain. Music, going to sing in a choir, group participation in the arts... But this is much more digging into yourself – private stuff.

Wasson: On their own, each one is a kind of separate jewel, [and] can seem quite, perhaps, introspective and... kind of individual. But the mass of all nearly ninety of them together, and the way that one navigates through the site using the 'randomiser' button, for example, makes them feel like they come into interesting points of tension and conflict and reinforcement. So it's a very vibrant encounter, I found, and the credit for that must really go to Zoe and our other colleague, Jenn Ashworth, who had the idea for having that navigation interface.

Zoe Lambert: I'm Zoe Lambert. I'm a writer and lecturer in creative writing. I run one of the workshops to help develop writing in pain and chronic pain. Sarah asked me to be involved because I've done quite a few community-based workshops; also because I come from experience of pain as a carer. And, having witnessed the unusual forms of pain, of multiple sclerosis, that my mother's had for twenty years... [and] how sometimes she'll try to describe the strange sensations, and really struggle because it's not just 'Oh, it hurts' – it's a lot different. And that really influenced my approach to the workshop because I was thinking around touch, and ways of describing sensation and feelings, and brought that in, in different ways, in the kinds of activities we ended up doing on the day.

Evans: As a carer, highly involved with something – an outsider, in many ways, looking into somebody's pain.

Lambert: Yeah, I kind of appreciated what you said before around finding it difficult to start writing about pain. And, in the workshop, I kind of wanted the activity to offer ways in – in how you might describe pain through metaphor and images. I did a warm-up exercise around fabric, which [hasn't] really got anything to do with pain, but I was thinking more about sensation, because even how [you] describe sensations and how things feel like isn't easy. So I brought in lots of pieces of fabric – you know, cut offs. I saw some, kind of, scratchy, soft things – fluffy, feathery – and used that as an opening exercise to write about the fabric and how it made you feel, and the sensations, and then, kind of, words that you associate with that feeling. And the sensation of touching it, and then if any images or memories were then generated from that. So, kind of using this idea of touch as a way to think about our body and how we feel, because you're not having to write anything personal there – it's more about the fabric.

And I often find that objects are very useful for tricking people into writing without worrying about it... and overthinking. From that, thinking about how you can write about pain through images and metaphors, and getting the participants to write lots of different ones. So that you're not... you don't feel like every word has to be precious. So, pain is a colour, an object, a place, a number, a city, a time of day, a sound, and [also] what pain isn't. And so, with the same idea: so, pain is not a colour, pain is not a certain object or place. If you write quite a few of them, you'll have lots of different ones, and maybe just one stands out, and you like that, and you're like, 'Aw yeah,' and then running with one and developing that idea. And, oh look, you've got a poem – and without even trying.

And also, I was interested in medicalised spaces as well. If you're ill or a carer, you often spend a lot of time in doctor's surgeries and waiting rooms and hospitals, which are very particular. And they smell certain ways, don't they? And there's a certain kind of look to them. So, I got participants to kind of write about that and... and I think that's another way in, and that sense of a moment, a moment of waiting.

Unknown speaker:

The way the scent of the air changes as the day goes on: the warming sweetness of morning; the sharp resin of fir trees as the sun heats the day; the cool, soft evening air with the ground and lake and all the waving leaves mixed in. The way the early evening light strikes the birches and makes them chiaroscuro dramatic. The way my feet burn. The smudged charcoal underbellies of terns over the green water. Their sliding paths through the air. This deep, stabbing pain in both temples. The buzzing

flight of sugar-fuelled hummingbirds. The way my entire body is filled with pain and unable to move from this chair. Heavily, here, just so. That bird, there, hopping from branch to branch. Almost hidden. The feel of my skin as a gentle breeze touches the side of my face. The things I long to do. That dragonfly, there, and the sun behind its wings. Every dancing leaf. The air again: changing.

Evans: 'In Stillness' – a fragment, a moment, contributed by D. Phoenix from Canada to the 'Translating Chronic Pain' project.

Now, I just need to remind you, as I always do, that 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 professional on any matter relating to your health and well-being. He or she is the only person who knows you, your circumstances, and therefore the appropriate action to take on your behalf.

You can download all editions of *Airing Pain* from Pain Concern's website, which is... painconcern.org.uk.

The 'Translating Chronic Pain' project is ongoing, so we can carry on submitting our own moments or fragments at the permanent website, which is: wp.lancs.ac.uk/translatingpain. Or just put 'Translating Chronic Pain Lancaster' into your search engine.

Wasson: The site has a lot of resources on it that would be of interest, including pain support, and information on the academic dimensions of the project. But the absolute priority of the site is the Anthology, and the Creative Manifesto, and we welcome submissions from anybody who feels moved to contribute. We don't mandate that they have certain kinds of pain, or that they are living with pain, or that they are specifically carers or practitioners, and it's international.

Evans: What sort of advice would you give to people who are listening to this now, who would like to write something, but they don't know how to do it?

Lambert: Get a nice new notebook, first of all. If you've followed the metaphor ideas, and then, kind of, the idea of listing different images, or ways in of describing pain, and doing a lot of it, and then writing lots of different images. There's a lovely writer called Natalie Goldberg, who's written a wonderful book called 'Writing Down the Bones'. And I think that's an amazing book for helping people to start writing, and throw off the shackles and fears, and any little voice in your head that might be saying, 'Oh, you're no good - you got terrible marks at school in English,' you know, or anything like that. And because it's all about practice... And starting a diary can be really good. The daily practice of writing, of just getting your thoughts and feelings down, and not judging yourself as well, not letting that little voice

in here say, 'Oh no, no one wants to listen to what you have to say' – anything like that. But just getting it down. And I think building up a writing practice of writing every day is really important. We always expect ourselves to write brilliantly the first time. That's not true. So you have to let yourself develop your voice and just get words on the page.

Wasson: There's a lovely poem that's occurring to me now by Ruth Victoria Chalkley, who submitted several beautiful works. And it's a response to getting new splints. So, taking just a moment, thinking of the moments and glimpses as an empowering framework, you know – just a *moment* in a day – she gets these splints, and she thinks about how they rattle, and kind of scrape, especially when they're new and [scratchy], as many of us will probably remember. So, little details like that – taking a detail and just hanging out with that detail, that moment of time, without the burden of trying to make sense of one's whole life in prose. Just, where are you right now? Sitting in your chair, standing, moving, thinking about something... Just that moment. Let's have that glimpse. Let that glimpse breathe.

Hirst: For me, the thing that I would say is: take the thought that you keep having that you can't tell people about – that you don't express to people. So, for me, for example, 'There is no God' – that's a thought that's gone through my head multiple times. But it's not something you talk about because then it becomes a *narrative* and a *drama*. A phrase that you know that the people who you're with won't be comfortable with you saying. Things like 'Don't go away, don't touch me... right now,' and you can use that, and develop from that. Use those things that you're not allowed to say or you're not allowing yourself to say, and work from there as another sort of place to start. Or take the thing in the other poem that I wrote; take the thing that you *always* say but that you're hiding behind, and let yourself be seen behind it.

Evans: And, what I would say, whether you write something or not, just read them, and that might inspire you to write.

Wasson: I think it really will because there's so many different ones, aren't there? There's such a range of voices, and so inspiring. Many people using photographs and artwork alongside it, too. Each really giving you a momentary glimpse. And, the more, the better, because pain needs to be seen and needs to be heard.

Contributors:

- Dr Sara Wasson, English and Creative Writing Lecturer, 'Translating Chronic Pain' Lead Investigator, Lancaster University

- Holly Hirst, PhD and Associate Lecturer in English, Manchester Metropolitan University
- Zoe Lambert, Lecturer, English and Creative Writing, Lancaster University.

More information:

- Translating Chronic Pain website: <http://wp.lancs.ac.uk/translatingpain/>.

Contributors:

- Dr Sara Wasson, English and Creative Writing Lecturer, 'Translating Chronic Pain' Lead Investigator, Lancaster University
- Holly Hirst, PhD and Associate Lecturer in English, Manchester Metropolitan University
- Zoe Lambert, Lecturer, English and Creative Writing, Lancaster University

Transcribed by Georgia Gaffney