

Airing Pain Programme 62: Independent living

How to get support in regaining independence and the physical and mental health benefits of social exercise.

How can people left disabled and housebound by chronic pain be supported to live independently? Producer Paul Evans visits two Edinburgh-based organisations with different approaches to transforming the lives of people in pain.

The Lothian Centre for Inclusive Living (LCIL) is run by disabled people for disabled people with the aim, as its name suggests, of helping people to live full lives despite their condition.

A key part of their service is supporting people as they apply for the benefits to which they are entitled in an often confusing and frustrating system. Jacqueline Todd recalls her struggle to be recognised as eligible for the Personal Independence Payment (PIP) and the freedom she has gained from adaptations to her home.

At the Thistle Foundation Paul speaks to members and staff about how their exercise and lifestyle classes bring people 'out of the darkness' of social isolation and pain. John Cunningham found the 'supremely fit' people at his local gym intimidating, but the welcoming and supportive environment has 'changed [his] life dramatically'. Course leader Linda Douglas talks about the importance of finding a 'safe space' where people can focus on their strengths and find out what works for them.

Paul Evans: You're listening to ***Airing Pain***, a programme bought to you by Pain Concern, a UK based charity working to help, support and inform people living with pain and healthcare professionals. This edition has been funded by a grant from the Moffatt Charitable Trust.

Margaret Hendry: It's not good for you to sit in the house, seven days a week, 24 hours a day, and speak to no-one and not see anyone.

Jacqueline Todd: Independent living – is everyone living the same? People with disabilities

are able to have the same quality of life as people who are able-bodied. It's our human right.

Evans: Chronic pain reduces the quality of life more than almost any other condition. One in four of us diagnosed with it will go on to lose our jobs and in just over one in five cases chronic pain leads to depression. It was the second most common reason given for claiming the old Incapacity Benefit. In this addition of *Airing Pain* I want to look at what help is available for those whose chronic pain has robbed them of their independence. The Lothian Centre for Inclusive Living – LCIL – is, as its name might suggest, in Edinburgh. Kirsty Henderson is its Information and Communications Officer.

Kirsty Henderson: It was set up by a group of disabled people who came together, who decided that they wanted to use direct payments as a means of having choice and control over their care and support. That was a relatively new thing that was happening at the time, direct payments. It was very much rooted in their experience and the organisation is still a user-led organisation. We're a part of the independent living movement in Scotland, we work closely with other disabled people's organisations to make sure that the voices of disabled people are heard at a national level, but we also provide a range of independent living services to support people to live independently in communities of their choice, regardless of their impairments as well.

My main role is co-ordinating the information service that we run called Grapevine. Grapevine is the Lothian Centre for Inclusive Living's disability information and advice service – we're the only specialist disability information and advice service in Edinburgh – we cover mid-Lothian and East Lothian as well. We were set up in response to the information needs that disabled people have – there's so much information out there and disabled people found that actually trying to pick up what's relevant, find stuff that's relevant and accessible to them was very difficult.

Therefore, Grapevine was set up on the basis that it would respond to their needs, it would recognise their needs, and we very much work on the principles of empowering and enabling disabled people, and their supporters, so they can get in touch with us to find out what their rights might be, what their entitlements might be, speak to somebody who is completely independent and will give them that information on a free and confidential basis as well.

We provide information in a range of formats, so we have our disability information line; we provide – more so these days – information and advice online via email; we also go out and do outreach talks – talks in the community – and that's quite an important way of actually informing people of their rights to certain entitlements: benefits, services and a way of getting

people into LCIL services as well. But we work with from people from the point of view of them as an individual and finding out from them what their needs are.

Evans: What are the burning issues that people contact you about?

Henderson: In Grapevine, about 40% of our enquiries – and our enquiries have risen in this area over the last few years – have been in relation to welfare reform and benefit changes. People are concerned about what's happening with some of the changes; people want to know what their rights are to claim these benefits; some people – and we're really lucky that we have got some really good partnership work happening with some professionals who will actively encourage people to contact us and say you need to speak to LCIL about what you might actually be entitled to. So in Grapevine we can actually find out where people are coming from, what their needs are and say 'Okay'... do a bit of a check to see that they are getting the help that they are entitled to...

And predominantly 40% of our enquiries are in relation to benefits. The main benefit we assess people with was Disability Living Allowance, but with that being phased out and the replacement benefit Personal Independence Payment, or PIP, as some people have called it, is now taking over from that, we've been helping individuals who have perhaps recently been diagnosed with a long-term health condition, or have recently been informed about our services and they've said, you know, get in touch with the service they can help you claim what you're going to be entitled to – so we used to help people with their Disability Living Allowance claims, now we're helping people with their PIP claims.

That's been quite a challenge, I mean, as a service we've had to learn a whole new benefit, a new assessment as part of that benefit. Like the DLA forms the PIP forms are huge – they can take up to three hours actually to fill in – which is quite a long time, but our advisors, we are, kinda trained up and skilled in being able to ensure that we get all the information we need from people in order for them to make a successful claim and get what they're actually entitled to.

Evans: Kirsty Henderson. Jaqueline Todd is a service user, champion and Grapevine volunteer for the Lothian Centre for Inclusive Living. She has fibromyalgia, arthritis and hypermobility syndrome. She told me how these conditions affect her life.

Jaqueline Todd: I lost my life, I didn't have a life, in pain 24/7, couldn't walk, I was practically bedridden – the depression that comes with that because your life has changed. I lost my partner of four years because he couldn't handle my illness. Fibromyalgia has so

many symptoms, but I think the worst one is chronic pain. It's very difficult for people to understand, because it can be a hidden disability. I don't want to say I look normal, because that's not right [laughs]...

Evans: ...I was going to say you look absolutely fine to me...

Todd: ...picture of health!

Evans: How am I supposed to know that you're ill?

Todd: You wouldn't. Nobody would. But, you know, people should be treating others as equals and not just taking things for granted. There's so many illnesses, people with impairments that are with chronic pain and are also... look there's so many hidden things, and there's no facts and figures to show, you know there's lots of facts and figures to say, 'so many people are in wheelchairs' and 'so many are this, that and the next thing' – nothing for invisible disabilities. Which I think is a disgrace really. I don't know how many times my GP has said to me, 'you're depressed'.

Well, yeah, I think you probably would be a bit depressed, I keep saying to my GP, 'I'm not depressed. I'm hacked off and I'm hacked off because I want to do everything that I could do before. I don't want to stay in the house. I want to go out.'

Now that social workers, etc. are involved, it's a case of, 'well, you're only allowed your Community Amount to get you outside for eight hours a week'. Where's the independence there? If I said that to them, you're getting out of your house for eight hours in any one week – that's awful.

Things have got to change. You know, if you can have a shower or a bath once every three days – do they only wash once every three days? People don't understand and I think especially with people who are in services which are meant to help us – if they don't understand, then...I don't know. It's just, disgusting. Absolutely disgusting. You have to meet the criteria; they don't tell you what the criteria is; they tell you about the indicative budget – I looked it up in the Dictionary – it doesn't make any sense to me, at all.

Evans: Indicative budget?

Todd: Yes. They're not sure if there's enough funds because of the indicative budget. Still don't understand it. Now the SDS, self-directed support, has come into play, helping us all,

wonderful thing. The champions have been helping to train the people who are training those in the council – social workers, Social Care Direct, but they've still not got the right answers. What does that say? I was told I would have to wait until next May before I could be reassessed. Why?

Henderson: You know, we can't live on fresh air, people have got bills to pay, rent to pay, mortgages to pay and often that's the priority for that individual when they first come into contact with us, so we can help them with that and get things in place for them so they can pay their bills and whatnot and then, if need be, if they have other requirements, we can refer them on to the likes of the Independent Living team who support people with care and support needs, can help them set up packages of care and support to use Self-Directed Support to enable them to live the lives they want to lead.

I should say, we've got quite a big training service within the Lothian Centre for Inclusive Living. All our trainers are actually disabled people themselves, so they have the experience; they have the insight of knowing what it's actually like to live with a long-term health condition or impairment. So that's quite unique. We train disabled people on how to become an employer of personal assistants so that they know what's expected of them in their role. We also train personal assistants as well, so people who are employed by a disabled person as a PA can come on training to find out about the social model of disability; how to ensure that they follow the ethos of what independent living is about so that that they can enable that individual to live as independent a life as possible with their assistance.

Todd: I practically begged and pleaded at the tribunal. I told them they were very unjust and unfair. I told the GP that was interrogating me exactly what I thought of him and that he shouldn't be a health worker at all, before I went out of the room in a dreadful state. And I shouldn't have had to have went through that – no-one should. It's disgusting. It's a disgrace. People who have an impairment, like mine anyway, they don't have the strength to fight. The people here at LCIL they were like 'you've got to. You've got to go through it, it's your right'. So I thought, right I will, y'know. And I did. But it wasn't a nice experience, it was awful.

Evans: What support and advice do people need before going into an assessment?

Todd: They need to know what's going to be expected of them. They need to know exactly what's going to happen. Because you're frightened. It took me maybe – after I'd had help here – it took me maybe three months before I actually had the guts to phone up – I wish I'd done it a lot sooner, but my Independent Living Officer kept saying to me 'Go for it Jaqueline,

you're entitled to this', you know? 'You need the help, so ask for the help.'

Evans: For people who don't live in Edinburgh who might be listening to *Airing Pain*, what advice would you give them?

Todd: If at all possible I would ask them to contact the nearest Centre for Inclusive Living, if there is one and get advice from there. Failing that, if there's not, contact Social Care Direct, and be honest. You have to explain what's wrong. A social worker then telephones you and you have to explain what's wrong again. And then someone comes out to visit you and you basically tell them your life story and how you're affected by things now. Then I had an OT, and Occupational Therapist, coming out to see me who was wonderful. I've got all these gadgets now: I've got grab rails in the bathroom; I've got a raised toilet seat; I've got a bed guard; I've got a perching stool in the kitchen; I've got a community alarm, so if I have a fall I can get in touch with them right away. Just having those appliances in the house has made a huge difference.

Evans: And that's independent living?

Todd: Well it is yes, yes. Not sending the Re-enablement Team out to shower me and help me to make breakfast for an hour in the morning and then in the afternoon come and help me make lunch for half an hour – that's not being independent, that's being looked after. And I felt, you know, as though they felt sorry for me.

Evans: That could feel like being a burden.

Todd: Yes, very much so. You feel kind of unworthy in society and second best and the, sort of, lowest of classes.

Evans: That was Jaqueline Todd and you can find more details for the Lothian Centre for Inclusive Living on their website which is www.lothiancil.org.uk. The support she receives and gives there is practical and is key to managing the nuts and bolts, if you like, of living independently in what is, essentially, a bureaucratic society.

The Thistle Foundation, also in Edinburgh, supports people with long-term illnesses or disability to help them cope and regain some control back into their lives but from a different perspective. Linda Douglas is part of their Health and Wellbeing team.

Linda Douglas: We run lifestyle management courses for people with long-term health problems, or living in difficult situations. We also do one-to-one sessions for people. We have a gym and exercise classes and we can support people in the gym as well. We also run mindfulness courses.

Evans: And who uses it?

Douglas: Anybody who feels that it would be helpful to come here. People come with all sorts of different conditions and illnesses. I guess we mostly see people who live locally in Craigmiller, but we also see people from all round Edinburgh and, further afield, we run courses – in fact two of our team have just come back from running a course near Inverness for veterans.

Evans: And do service users have to qualify in some way?

Douglas: Not at all no. If they feel that this service is going to be helpful for them – and we usually meet them before they decide on what they'll access here and talk about what's available and a bit about our approach and the way we work. If they feel that something here would be helpful for them, then its open doors for them, yes.

John Cunningham: I'm John Cunningham. I come here for general fitness. When I first came here I could hardly walk, I was using a Zimmer. The one to one with a physiotherapist called Diana, who had me under her wing for nearly nine weeks before I was allowed anywhere near the gym, taking me through basic steps getting me back to walking. Honestly, I never thought I would get back to walking again without a Zimmer. Now I'm walking with a stick, the difference it's made to my life is absolutely unbelievable and this place has been a bit of a god-send for me.

Evans: And what stopped you walking in the first place?

Cunningham: I used to be a postman and I was knocked down with a motorbike while I was on delivery. A young lad came down the pavement as I was coming out of a garden and ran into me and things just went downhill, I ended up being medically retired. I had a couple of people out from Leith medical centre, physiotherapists, and they were massaging my legs, feet, and suggested the Thistle Foundation would be a good idea.

I was a bit dubious about coming here to be honest, because I had tried a gym up in my local area up in Gracemount and it was people who were supremely fit and I felt totally out of

place. I just didn't like the idea of being there while these people were running, doing everything I wanted to do but I couldn't so, and I felt a bit out of sorts about that. And when I came here I was a bit surprised at how easy everything was, how welcoming it was, how people treated you, made you feel welcome.

Evans: Gyms can be very, very intimidating places, for people who've never been to a gym – the thought of all those Lycra clad very, very fit muscular bodies and certainly for people like me that is intimidating.

Cunningham: It was very intimidating for me, the fact that I was on a treadmill at very, very low speed and getting a tap on the shoulder to basically say, 'are you finished, can I go on that?' And I just felt out of place there. It didn't matter what I was trying to do, it was always people were supremely fit, physically fit and I just felt very, very intimidated by it and I just stopped going. And as I say, when I came here I was a bit apprehensive, thinking it would probably be along the same lines and I was totally surprised how different it was, how welcoming it was, how people went out of their way to help you. As I say, I've been coming here for five, six years now and the difference it has made to me is absolutely outstanding. My life's changed dramatically since I came here.

Evans: In what way?

Cunningham: The fact now that I can get out, I socialise. I found before when I was stuck in the house I had nobody to talk to, it was just me and my wife and it came to a thing where we had nothing to talk about because we were seeing each other all day and basically, conversation just seemed to dry up. Now, it's totally different, you're going home with stories, people you've sat beside, they tell you things about what's happening with their families and it's a totally amazing place to come to. I mean people go out of their way, as I say, to make you feel welcome.

Evans: You mentioned the gym – it sounds to me as if the social side and the support side is as important as the physical side.

Cunningham: Oh it's very important, yeah. You've been at work before, where you socialise with your friends and when I was retired that was all taken away from me. And the fact that I had to stop work that I couldn't get out, I really thought my life was over. Depression was something that I'd never heard of, but when all this happened, I felt a kind of depression, and

it was unbelievable how everything just seemed to get on top of you, whereas now, completely different.

Hendry: I'm Margaret Hendry and I'm a volunteer at Thistle Foundation.

Evans: So, why did you come here in the first place as a client?

Hendry: I came here to, what was called at that time a 'back class', because I've got chronic problems with my back. And anyway, I went through the class and then I went away and I decided, no, I can do all that myself at home, so I just didn't bother. And then eventually I did come and started coming to classes that other people were in – I did the lifestyle courses, the gym-based ones and I did 'Branching Out'.

Evans: What's a lifestyle course, what is lifestyle?

Hendry: It's a different way of looking at the way you're leading your life and looking to see the changes you can make. It's showing you a different level, if you like, of what you can gain from life.

Evans: Can you give me an example, from things you might have learned?

Hendry: Things I learnt – it's not good for you to sit in a house, seven days a week, 24 hours a day and speak to no-one and not see anyone. It helps you to come into a group and just come and sit among other people – if you don't want to speak, that's fine, don't speak – just come and sit.

It shows you that you're not on your own, that no matter how you feel there is always someone there who can help you get a wee bit better. And it won't happen overnight; it won't happen maybe in a week, but it will eventually happen, and those people are there and bring you out of the darkness. Because that's all it is, it's just a big, dark hole, and the further you go down that dark hole, the harder it is to get out of it. But come to Thistle Foundation and someone will help you get out of that hole. And that's what I did.

Evans: One thing that occurs to me about being in a group of people with similar conditions – that it could degenerate into moaning sessions.

Cunningham: That was a thing that never happened. People wouldn't say, 'this has

happened to me'; 'this has happened to me, why's this happened to me?' We never actually had anything like that. Someone would always say 'well, what happened to you?' And you told them your story and they'd be, 'Oh, I'm sorry to hear that', things like that and then they'd maybe tell you a wee bit about themselves.

But it was like everything else, nobody opens up right away and tells you everything that's happened to them, you get wee bits and pieces and as the group goes on you do form a social group, you start talking about things, everyday things, and then family life comes into it, but I've not heard anybody saying, 'Oh God, I wish I hadn't come here' or 'this is boring me, or that is boring me'... I've honestly never experienced that in any of the groups I've been in.

Hendry: I found, when I started coming in here exercising, it took away the pain. It didn't add to the pain, it actually took it away. You actually went out as if you were bouncing – you'd maybe come in really, 'urrrrggghhhh', but by the time you'd exercised, you'd met different people, you'd taken the time to have coffee, a blether, whatever, you actually floated out, you float out on air. And the exercise gets an awful lot easier and your pains get an awful lot better. They never go away, but they're easy enough forgotten.

Evans: And the advantage of a place like the Thistle Foundation is that with a pain management course or therapy – it stops. This continues.

Hendry: As long as you want to be a member here, yeah.

Cunningham: See, I've found in the groups that I'm in as well, everybody enjoys being here; they actually look forward to being here. And if they're ill, they miss this place, they're desperate to get back and that is something that's totally amazing, that people are like that where they're into a thing that they thoroughly enjoy. And if they do miss it, they come in and they say, 'Oh my God I've missed this', or they've been on holiday, they say, 'I'm glad to be back, I'm glad to be back in the group'. And it's an amazing experience, the fact that people from all different walks of life are coming here.

Evans: Lots of our listeners will not be in Edinburgh, they'll be throughout the UK and throughout the world, what advice would you give them to find a place like this?

Hendry: I wonder if I described our approach, the way we work, if that might help people to source the right kind of help, because everybody's different. As Margaret says, we have a

non-expert approach, which means that we don't believe that we're expert in other people's lives, so we don't advise or tell people what they should do or changes they should make, but I guess, rather we create a space where people can find that out for themselves. We do focus on things people are already doing that's helpful, that's working, so they can build on that, or if times are particularly difficult, how they are getting through it, how they're coping with it. And so really we're focusing on people's strengths and their resilience I guess.

If people find the ways they're coping are not helpful, which is sometimes the case, then perhaps they might want to do something different and that's where, on the lifestyle courses anyway, we explore different lifestyle skills, self-management skills, if you like. Maybe that's where they will find something that's more helpful, that they can put in its place. So our focus is on what's working – if it's working, do more of it – if it's not working, do something different.

Evans: How important is it that people with chronic pain, your clients, seek medical advice before jumping into the gym?

Hendry: We're not medically based and so, as with any gym, if they're going to join the gym, do a basic health questionnaire and if there's any information we need further, or advice from their GP, then people are encouraged to do that. But we really encourage people to pace themselves and listen to their body and it's important not to push through pain barriers when you're exercising, so underdoing it initially is probably a good way to start and building up slowly from there so you don't exacerbate the pain.

Evans: That's easier said than done.

Hendry: I know. We never said it would be easy and I guess that's one of the topics we look at in the lifestyle management courses – pacing.

Cunningham: Pacing is a thing I find very hard. It's a small word, but it's a very, very hard to get your head round. I used to have a lot of problems with flare-ups. I used to go every month, bad flare ups, couldn't move, everything would seize. GPs had to come out and give me injections, muscle relaxants, to help me get back into a routine.

Over the last four years, I've not had one flare-up through the gym work, just coming here and the difference that's made to my life is amazing, to my family life, even my family notice the difference. It just shows you that putting in a wee bit of work and effort, it does help you in the long run. You're doing the treadmill, the exercise bike, a wee bit of weights and it's

amazing how a bit of exercise can make your life so easy.

Evans: John Cunningham. And I just have time to remind you that whilst 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 wellbeing. He or she is the only person that knows you, and your circumstances, and therefore the appropriate action to take on your behalf.

Don't forget that you can still download all editions of **Airing Pain** from our website, its painconcern.org.uk, or you can obtain CD copies direct from Pain Concern, and the website for The Thistle Foundation is www.thistle.org.uk.

Last words to Margaret Hendry at The Thistle Foundation...

Hendry: You don't have to pay hundreds of pounds for a pair of trainers; you can get the cheapest sand shoes, whatever. You don't have to spend pounds and pounds on Lycra and you come in and wear what you're comfortable wearing, as long as you've got really good, decent footwear that's all you need. You're not only helping the pains in your body, it's like bringing the whole person out. You're not just getting rid of feelings that you can actually feel; it's your mental health as well as your physical health. And this is the most wonderful little nest egg. And if I start talking about Thistle Foundation I go on for hours and hours and hours so I'm gonna stop now, because I'm just so passionate about this place.

More information

You can find out more about the organisations featured in this programme at:

www.lothiancil.org.uk

www.thistle.org.uk

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