

What is self-management?

'You have to want to live again.' That's the key to managing pain, according to Diane. It can be a long, winding road, but many people living with pain have learned strategies that help them to get the most out of life alongside their condition, rather than being dominated by it.

Top tip: *make pacing more appealing. Start by choosing an activity you find rewarding and enjoyable. Then, build up slowly and steadily to doing more.*

Find out more: *Pain Concern's booklet [A Guide to Managing Pain](#) is a great place to start learning about the things you can do to manage your pain, including pacing and dealing with flare-ups.*

Christine Hamilton: I'm in pain 24/7, so 24 hours a day, seven days a week.

Dianne Connor: It's hellish pain at times, I mean it's just a monster.

Helen Rice: I was in a lot of pain, trying to hold on to the straps, or doing all the things that you have to do as a commuter.

Hamilton: It never goes away, it does flare up depending what I'm doing, what activity I'm doing. If I push myself too much, then it flares up more.

Rice: I was struggling and it was becoming very stressful, because if I couldn't get a seat then I was going to be sore for the rest of the day, and extremely tired.

Connor: I call it the dragon, because it undulates and does so many things and breathes fire.

Rice: I actually went into hospital for three weeks and during that time I learnt a lot about the pain cycle and self management techniques. And, really, I suppose I had the revelation that there was not going to be a pill that would fix this and there was not going to be an operation that would fix this and that basically this is the body that I have, this is how it will always be, but there are things that I can do to help manage that body to make it as good as it possibly can be.

Hamilton: It means that I can't do the things that I used to be able to do, but I've accepted that now, with the training that I've been given. I was very fortunate to be lucky enough to be accepted onto the Glasgow pain management programme. And on that programme – it was

a ten-week, half a day a week session and we were taught different tools and techniques to help to self manage pain ourselves.

The kind of things were understanding our values, what's important to us, setting some goals and then from there setting an action plan which would help me become more mobile, more flexible and achieve my goals.

And then after that they gave us a toolkit of different tools to pick on, from things like hot words, using hot words and what they mean to us. 'So I can't do this', 'I won't do that', 'I'm going to be sore if I try this'. To acceptance, so acceptance commitment therapy, which was a tool that they taught us which I hadn't come across before, which is around accepting what you can and can't do, accepting that I'm going to be in pain for the rest of my life now.

Connor: I don't think you really move on until you accept your pain. Once I was moved on to the pain clinic I got a psychologist. She said 'there isn't one day you waken up and there's a great big banner with balloons that says "acceptance"'. She says 'you don't just suddenly waken up and go, "I've accepted what I've got, I've accepted my pain"'. She says 'it's a long journey that you're on and you'll slip on and off the path, the road will twist on your journey. But in the end', she says, 'it's just a gradual thing'. And that's how it happened. I can't tell you the day I accepted I had CRPS and I had chronic pain, it was just a slow progression.

Rice: I had very simple physiotherapy to start with. I was exhausted, I couldn't do very much at all, but once I left hospital I had a fantastic community physiotherapist who visited me at home so that I didn't have to get to appointments, which had been a big problem in the past. And we just built it up from there and eventually I was well enough to go swimming, so I swam. I remember going into the swimming pool, hadn't swum for many, many years, I got in the water and I swam one length and then I got out.

Hamilton: If you change your language to say, 'I can't do 10k, but I can do yoga', so it's different ways of doing things. 'I can't pick this up, but if I move differently I might be able to pick that up.' So it's a kind of positivity around your negative thoughts and noticing how often you do that, because they drag you down. So for me probably 80 per cent of the tools that I learnt were around the mind and using the mind much more effectively.

Rice: A few days later I did the same, but I swam two lengths. And I said that once I could do forty lengths, which is what I used to do years ago, that would be a sign that it was time to find the next kind of physical goal.

Hamilton: I think if you don't have little goals, you're kind of aimless, you don't have anything to achieve for, or get out of your bed for in the morning when you are sore. So little

things, little tiny goals, like I'm going on holiday this year. So to be able to be planning for next year, or for in six months, or even tomorrow is a huge life change for me, because I couldn't plan any day before. I didn't know how well I was going to be each day. So for me I know I can commit to going to London in September and know I can go on holiday in June, so I know now that I can do that. So that's commitment for me and aiming for things and putting in place different techniques to get me there.

Connor: Somebody told me this early on, that somebody with chronic pain, you only have so many spoons in a day and every day how many spoons you have to use is different and so instead of saying 'I'm having a bad day' or whatever, we talk about how many spoons I've got. So I'll say to my husband Paul, 'I've not got many spoons today' or 'I feel I've got a lot of spoons today'.

So that helped me learn, because I did the typical things. When I had a good day I would just rush about and try and do things and then I'd be bedded and I'd be ill for days or weeks after. So I then learned how many spoons I had in a day and I learned that I could actually start to do things.

I think they use it as pacing as well, but I don't like that word, because the hospital, everybody was ramming that down my throat, pacing, pacing, pacing. So in our house it's called 'the P word'. Because I don't like that word anymore because it drove me round the twist because I couldn't learn to pace in the beginning, you know, I would try and do something with my hand and the pain would just be... you know, so I found how many spoons I had works.

So that was how I started realising that in amongst exhaustion, the tiredness, the pain, that if you learn just to do a little bit, then a little bit crept on to doing a little bit more, a little bit more.

Rice: The tactic of pacing is one of the hardest things that you'll ever try and learn to do. And you almost have to keep relearning it, or I do anyway, because your body and mind, it doesn't come naturally, I think, to a lot of people. The temptation is always to do a bit more, and then when you have a flare up and you have a bad day it can be very disheartening.

Hamilton: Pacing is really difficult for me. It was something that I hadn't known anything about before, I hadn't come across it before, because I was always a hundred miles an hour at everything, so car at full throttle is the way I explain it. And obviously if you do that with a car bits fall off and that's me, that's me in a nutshell. I know now that I've got to change

gears for different situations. I know now that I've got to sit quietly sometimes and gather my thoughts and re-centre myself and I use my mindfulness for that and yoga for that.

Rice: One of the things they explained to me in the hospital, we sort of mapped it out, was when you live like that, in the boom-bust cycle, you might start off with having a good day and a bad day. And over the course of time what you end up with is a good day and then six bad days and the recovery time seems to take longer and longer.

Hamilton: For me pacing means if I'm in the office, I don't wear heels, if I'm out of the office I wear high heels. If I'm in the office and I'm sitting at the computer a lot, we've got intelligent lighting so it'll go off every half hour, so I move. And I don't just move a wee bit, I'll go up to the different floor to go to the toilet. So there's all different things about pacing in there.

It's about knowing your limits, and not pushing yourself so you have that, you're fine one day, lying flat on your back the next day, you're fine the next day then you... So it's about finding that balance, what we call 'the baseline'. And then from the baseline it's like pushing on each, not pushing on, but moving forward each day a little bit more. So I now can do the gym, I can now do, you know, two and a half k walk, but I can't do a 10k run.

Rice: It is a continual battle to remind myself, you can't do all the things. Prioritise, I rule my life by an online calendar, where I colour code rest time, as well as activity time and try and stick very closely to that. It's not always possible, but wherever possible.

Hamilton: Pacing is still difficult for me, it's something even today, it's a mind thing for me now, I need to change my mindset, because my mind is still at a thousand miles an hour, but my body is not anymore. So I've learnt how to listen to my body, and manage that. But my mind is still a thousand miles an hour. So for me, that's where my mindfulness comes in and my yoga, I do yoga every morning and at classes at night. So for me that's when I get that time out. The stopping and then I realise. So sometimes I have to catch myself, that I know I'm pushing too far, or too hard and I just stop. I can just let things go now.

That's something I couldn't do before, was let things go. So, for example, when I was doing the garden before I would blitz it in an hour and a half. I can do a bit and go off and have a cup of tea and then do another bit and then come back or maybe another day and do something else, because I still enjoy doing it, but I can't do it as fast. And I'm not frustrated anymore, that I can't do it that quickly.

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