Chronic Pain Ireland

Stories that Move You

Taighde Éireann Research Ireland

DCU Ollscoil Chathair Bhaile Átha Cliath Dublin City University

Introduction

Living with chronic pain shapes your relationship with movement, whether pain has been part of your life from the very beginning or arrived later on.

In this booklet, 5 people living with different pain conditions share, in their own words, what movement looks like for them.

We explored the setbacks, the small wins, and the ways they've learned to adapt and work with their bodies.

These aren't stories about pushing through pain. They're about finding your own version of movement, however small that starts.

Chronic Pain Ireland

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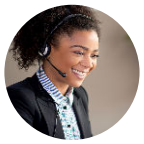


Sharon's Story

Growing Up

I was fairly active as a child. I walked everywhere and had great stamina, which was something my parents commented on. If there was a wall or a tree, I'd be climbing and falling off it!

I did dance and drama from about 6 until 14, and there were quieter stretches of TV and computer time. I walked, cycled and swam every chance I got.

7 Years on pain journey

Living with Chronic Pain

I've been living with chronic pain since around 2019, when I was diagnosed with fibromyalgia. It started with extreme muscle spasms and long periods where I couldn't walk or was completely bedbound. Later I was treated for hypermobility and Polyendocrine Metabolic Ovarian Syndrome (PMOS).

Over time, learning to pace myself has been a lifesaver. I began slowing down, becoming more mindful in my movement, and listening to my body before it reaches its limit.

Hypermobility

PMOS

Fibromyalgia

Overcoming Hurdles

A major hurdle has been relearning how to walk and move, rebuilding my capacity very slowly over weeks and months. My pain fluctuates a lot.

Some days I feel strong and capable, other days I can barely lift my head from the pillow. That inconsistency makes it difficult to trust my body or plan ahead. A phrase I keep in mind is "stop before you have to stop."

Adapting Movement

On high-pain days, I try not to become completely rigid or still. I focus on small, gentle movements throughout the day like rolling my shoulders, nodding my head, lifting my feet off the floor, and if I can manage more, I'll stand and stretch.

It's about moving within what feels manageable, and giving myself permission to rest, cancel plans and pace myself without guilt.

> "Stop before you have to stop"

Words of Wisdom

Reach out to people who understand it... being genuinely heard makes a huge difference. Organisations like Chronic Pain Ireland offer resources where you can learn and feel less alone. Treat it as a continuous learning process.

What works for one person may not work for another, and what works one day might not the next. So just keep trying and be patient with the process. Take it one day at a time. That's really all anyone can do.

Ross's Story

Growing Up

Growing up, there were no limitations as I was a normal, healthy lad. I played football before the age of 11, rugby from 11 to 15, karate from 15 to 18, and American football from 18 right up to now, at 39.

There was also a bit of boxing and rock climbing thrown in along the way. The social aspect was a big part of it. I realised it was the social and teamwork side that pulled me back to do American football.

4 Years on pain journey

Living with Chronic Pain

I've been living with my condition for 4 years now. After my third bout of COVID I wasn't recovering and I was tired all the time. I moved into coaching, but even walking the sideline was sometimes too much. I tried to shake it off by myself by going out running or walking, but that just led to some really bad post-exertional malaise.

Eventually, through my GP, I was referred to rheumatology, who brought in a physio. They carefully managing my heart rate, weights, intensity, and that made a huge, difference.

Overcoming Hurdles

Pacing has been the big one. I'm better at managing my energy, but with ADHD I always want to be on the go. Early on, pushing through work, sport and social life all at once led to crashing daily.

I had to take a year out of work. Acceptance took a while too, and it's still a challenge at times. It has helped me plan ahead and not being afraid to ask to sit where I'd be expected to stand.

Adapting Movement

> "Accept help & stack all the small adjustments"

On a low-energy or high-pain day, I'll hide away to prevent sensory overload. A bad episode will knock me out for a minimum of one day. The pain starts through the roof, then eases back, and I can push a little further, very cautiously. Coming out of a bad patch I'll try yoga.

For the first two years I did nothing, but yoga is the one I've kept returning to. That, and a bit of walking, is how I rebalance and recentre before going back to team sports.

Words of Wisdom

You're not alone. Support groups such as Chronic Pain Ireland, Long COVID Ireland, and on Facebook were helpful to me. It felt like it was just me. Even if no one had solutions, hearing "that happened to me too" helped me feel seen and calmed things down.

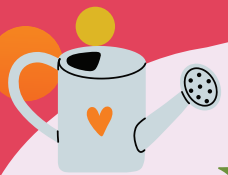
Focus on your health and learn about pacing. That was a game changer for me. Accepting help from those close to me supported my return to work. Stack the small bricks and eventually you've rebuilt your house. Maybe not the same as it was, but it's still standing.

Fionnuala's Story

Growing Up

I wasn't a big sports participant at school. I had an exemption because of pain, plus undiagnosed endometriosis. Outside school I was active in dance, musical society, swimming and family walks. There'd be pain afterwards, but I'd still be out playing.

Nobody knew what was wrong until I was diagnosed at 17. Real, structured activity only came in the last 10–15 years, once I was told to move for my own health.



40 Years on pain journey

Living with Chronic Pain

I've been living with pain for over 40 years. I still can't lie on my tummy as my back is arched so badly it's now fused that way. I've had several surgeries to fuse the joints in my pelvis, but they all failed. My pelvis is more triangular than oval, so the joints worked loose again.

After injuring myself lifting a bin, I ended up in hospital having my pubic symphysis fused. I spent three years in a wheelchair, and I've needed to use crutches outdoors since 2013.

Endometriosis

Ankylosing Spondylitis

Overcoming Hurdles

Cost and access have been big ones. When hydrotherapy was recommended there was only one small pool that did it, it involved travel, and it cost £70 a week.

Years later, when the medical exercise team I knew so well moved on, I was left trying to adjust to a new team who didn't know what I was able for, and again it was costing a fortune. I adapted my shed and put in my own exercise equipment.

Adapting Movement

I know when I wake up what kind of day I'm going to have. It can take me a long time just to get up. I take my tablets after breakfast and take stock. What keeps me moving is having something in the diary every day such as coffee or lunch with a pal.
It gets me up and takes my mind off the pain.

The change of seasons hits me hard. In Spring and Autumn my pain is really bad. I know once the weather settles so will the pain.

> "Put something in the diary to keep moving"

Words of Wisdom

Educate yourself and find the best doctors. If you don't like the first opinion keep getting opinions until you've run out of road. If somebody is gung-ho about surgery, get an opinion on that too.

Don't do anything on a whim. Then weigh it all up and see what's right for you. Keep yourself active. I spend hours in my garden, pottering, with a podcast on, and my mind just goes elsewhere. I get great satisfaction out of helping others. I am in a community choir which helps my mental health in the dark winter months.

Tom's Story

Growing Up

I grew up in the 80's so I was out on the green playing soccer from morning til night, and then under-age team soccer on weekends. Maybe some tennis on the road when Wimbledon was on.

There were no phones, no computer games, just a very active childhood. I played soccer up until 17 then got into running in my early 20's, ran races from 5k to marathons and everything in between, both in Ireland and abroad.

15 Years on pain journey

Living with Chronic Pain

I started having back problems in late 20's. I had a few back spasms and slipped discs, some of which resulted in a hospital visit. Ultimately ended up with a full disc herniation and micro-discectomy, and was left with permanent numbness in one leg and associated chronic neuropathic pain.

I have now been living with it for 15 years and I have had to re-learn how to walk without feeling in one leg, and how to manage the pain.

Neuropathic Pain

Overcoming Hurdles

Mentally going from running 4-5 times per week to barely walking without intense pain, in a short space of time, was tough.

Understanding how to best manage the pain took me a long time, and I have made a lot of mistakes on the way, but its been worth it.

In recent times I have ran a couple of (slow) parkruns, and even played a bit of padel (racquet sport).

Adapting Movement

My pain typically starts at night, so a high pain day follows a no-sleep night of intense pain (like a burning, throbbing pain).

Exercising / tiring myself out is the best way for me to manage the pain, which is hard after being awake all night, but if I can do it, it really helps.

> "Find the mix that means you can manage"

Words of Wisdom

The solution might not be one thing...it might be a mix of physio, exercise, pharma, nutrition, acupuncture, heat/cold, compression, surgical etc.

Keep trying until you find the mix that means you can manage. Also adapt your expectations – low-level chronic pain (that you can manage mostly) is worse than no pain but infinitely better than frequent high-level pain.

Ben's Story

Growing Up

From an early age, I was extremely active, running, dancing, football, and later rugby, golf, cricket, snooker, and chess. I was full of energy and always on the go.

Whether at school, sports clubs, or community activities I loved being involved with people. From age 14 I had part-time and summer jobs. I kept up a busy, active lifestyle into my late teens.

23 Years on pain journey

Living with Chronic Pain

As an adult I began experiencing widespread pain, which I first put down to years of physical work and sport. Fatigue crept in too, but I kept pushing through with over-the-counter painkillers rather than seeking medical advice.

Everything changed when I got shingles and my mobility deteriorated significantly. After years of investigations I was finally diagnosed with chronic fatigue syndrome and fibromyalgia following assessments by a neurologist and rheumatologist. My GP stayed supportive throughout.

Osteoarthritis Diabetes
Fibromyalgia

Overcoming Hurdles

Alongside fibromyalgia and CFS, I've also been diagnosed with diabetes, osteoarthritis, asthma, sleep apnoea, and heart conditions that run in my family.

Managing multiple long-term conditions is a daily challenge, and I've had to continually adapt my life around them.

Adapting Movement

I've learnt that gradual movement is essential. Gentle walks, chair-based exercises, yoga, and Tai Chi all help me maintain mobility without overexerting myself. Even a short walk around the house, garden, or local park helps, and on tougher days, the key is not staying seated too long.

Adopting a dog has brought a lot of joy, getting me out into nature on good days and keeping me company on the bad days. Neighbours are good about stepping in if I can't manage to walk the dog.

> "Work with both your mind & body"

Words of Wisdom

My message is simple: don't let it defeat you. Work with both your mind and body, one small step at a time. Joining a support group was one of the most valuable things I did. Meeting people through Chronic Pain Ireland who understood made a huge difference to my mental health and coping, and I realised I wasn't alone.

Working with a pain specialist has improved my mobility. The pain and fatigue haven't gone, but I refuse to let them define my life.

My Movement Journal

A non-judgmental space to celebrate how you moved your body today.

Quick Tip: There are no 'zero' days here. A 2-minute stretch while the kettle boils counts just as much as a 20-minute walk. Fill this in whenever it feels helpful! It is a great way to notice patterns in how your body responds to movement, celebrating your consistency along the way.

Date / Time	What Movement I Explored (e.g., walk, chair stretch)	How Much I Did (e.g., 5 mins, 1 set)	How My Body Felt / Reflection (e.g., relaxed, a bit tender)

Weekly Reflection & Gentle Wins

What went well this week? What did your body enjoy? (e.g., 'Loved doing my shoulder rolls in the morning', 'Pacing helped me avoid a severe flare-up')

Words of Wisdom

"Accept help & stack all the small adjustments"

"Put something in the diary to keep moving"

"Work with both your mind & body"

"Stop before you have to stop"

"Find the mix that means you can manage"

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