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Health
The advice you need

True-life PATIENT CASEBOOK

Breaking stigmas

Not all illnesses are visible and I'm proof of that

Priyaneet Kainth, 33, Birmingham

As my classmates sat cross-legged on the floor for the school assembly, I felt their stares.

Because, unlike them, I was sat on a chair.

I hated that I couldn't just blend into the crowd.

See, under my trousers, invisible to everyone, I wore leg splints.

Protecting my ankles and legs, they helped prevent injury.

But they left my legs burning, with ulcers.

I wore Piedro boots too, designed to relieve pressure on my feet and ankles.

At birth, I'd been diagnosed with mild cerebral palsy, muscular dystrophy and ataxia.

They were all conditions that left me with little muscle control.

Prone to falling over, I couldn't play with the other kids.

Comments from the bullies stung.

'What makes you so special? Cripple!' they'd taunt me.

I struggled with swallowing too, hardly eating at lunch.

My parents Vijay and Jatinder took me back and forth to doctors.

But there was little research, even less among South Asian people.

At secondary school in 2003, things got worse.

The first year was tough and I'd ring Mum from school.

'I don't feel well,' I'd fib, so she'd agree to collect me.

But over time, I came clean.

'I'm being bullied,' I cried.

Mum and Dad were brilliant, speaking to the school, who put on an assembly about invisible disabilities.

They fought to get me extra support too.

One-to-one help, extra time in exams, a note taker...

As a teen, I got trainers with built-in orthopaedic insoles and ankle splints.

A lifesaver.

Without them, I walked on tiptoes, as my cerebral palsy caused short tendons in my ankles.

In 2008, I started college, followed by uni for a degree in computing for business.

It was only in 2012 when, after years of appointments, docs had a new diagnosis.

Despite the challenges, my disability gives me purpose

'You've got Charcot-Marie-Tooth 4C,' the consultant said.

Known as CMT, the inherited disease is a group of conditions damaging the peripheral nerves.

It's incurable, but I was told therapies could help.

Tests confirmed that both my parents carried the defective genes.

And out of my three siblings and me, I was the only one with the condition.

Still, I was determined to keep living life.

Regardless of the stigma from my community.

'You must've done something bad in a previous life,' people would say.

It only made me stronger.

After graduating in 2014, I got a job at an investment bank and then moved away for a fresh start.

But when lockdown hit, I moved back home.

Now I work as a disability coach and diversity and inclusion leader. It's a job that I love.

I'm always in pain somewhere in my joints.

Every week, I have private physio sessions.

Plus podiatry every six to eight weeks, speech and language therapy every six months.

But despite the challenges I face, my disability gives me purpose.

It can be lonely but I pride myself on independence.

I drive, travel, swim, see friends and volunteer for Muscular Dystrophy UK.

I'm helping them to expand the South Asian neuromuscular community.

I can let my disabilities hold me back. Or I can educate people, make a difference. So that's what I'm striving to do.

Find out more

Visit musculardystrophyuk.org or call the free helpline on 0800 652 6352 (Mon-Thu 10am-2pm).

Turn over for more health

WORDS: MISHAAL KHAN PHOTOS: JOANNA RITCHIE, MUSCULAR DYSTROPHY UK