I’m not proud of being disabled. But I’m damn proud of how I show up.

It’s 1pm and I’m exhausted.

The pain in my bones is asking , no, begging for pain relief. But I know what happens next. Take meds now and my brain will be useless for the rest of the day. So instead, I grab another coffee, push myself a bit longer. Try to meet the deadlines. Try to prove I’m still capable. Still valuable.

Mostly to myself.

And it’s got me thinking. What does Disability Pride Month even mean? Because honestly? I’m not proud of being disabled.

I didn’t choose this. It doesn’t define me. (Well that’s my story though sometimes my body disagrees with my brain) It’s not some badge I wear with joy. But I am proud. Proud of how I keep showing up. Proud of the life I’ve rebuilt. Proud of the strength it takes to create a new normal when your old one disappears without warning.

And I share this not for sympathy. That’s never the goal. I write for awareness.

The invisible illness paradox

Because when your condition is invisible, the disbelief is visible. It’s in the way people look at you sideways. It’s in the patronising comments dressed up as compliments.

“Oh, but you don’t look sick.”

“You look great, though!”

“You’re just tired… we’re all tired.”

They say it like I should take it as a win. Like makeup and a smile mean my symptoms don’t exist. Like there isn’t an unwelcome lodger inside my body, a condition that can’t be cured, only managed. Badly.

The reality is: the world still doesn’t get invisible illness. And I don’t just mean your neighbour, your boss, or your gran.

I mean the medical professionals who gaslight you because your symptoms don’t match the boxes on their tickbox diagnostic tool.

The HR teams who performance-manage you for your absence record, not your attendance effort.

The friends who stop asking how you are because you haven’t had “good news” for a while.

And when the tests come back inconclusive, they call you dramatic. Or deluded. Or lazy.

Anyone who knows me would never use the term lazy as a description. I am surviving. And survival takes energy most people don't even realise is being spent.

The chronic illness economy of energy

You learn quickly how to ration energy like currency.

You mourn the body you used to have. You let go of spontaneous plans, late nights, and full social calendars. You map your day around what's "useable" and hope that your body doesn't pull the rug halfway through.

You watch friendships fade, not out of malice, but misunderstanding.

You get tired of explaining why you missed another event. You stop justifying hospital appointments. You swallow the guilt that clings to every "sorry I can't make it."

And then there's work. God, the workplace.

You do your best. You deliver. You drag yourself in on the days you shouldn't. You work twice as hard to get the same results the old you over-delivered. And still you're judged by the days you missed, not the courage it took to make it in when getting dressed and sorting your hair out deserved an Olympic medal.

The constant need to prove yourself isn't sustainable. It's exhausting. And ironically, that stress? It flares the illness. So the harder you try to stay employed, the sicker you get.

It's a vicious cycle, and one many of us opt out of entirely not because we "gave up," but because traditional employment gave up on us.

So we pivot.

We start businesses, become freelancers, consultants, creators. Not because we're chasing a dream but because we're tired of being treated like liabilities when we're actually leaders with lived experience.

When the diagnosis becomes your identity (against your will)

SAPHO syndrome. It sounds like a made-up acronym, something out of a sci-fi series. But it's real. It's rare. And it's a diagnosis I didn't ask for, didn't understand, and can't pronounce all the components still to this day. A sternoclavicular bone mass - that can't be chopped out or shrunk (a parasite that's most unwelcome)

It affects 0.4 in a million. And now, I'm one of them.

I didn’t just lose my health. I lost friendships. People I thought would be there… weren’t. And when I asked why? I got silence. Maybe I made them uncomfortable. Maybe I reminded them that illness doesn’t ask permission. Or maybe they just didn’t know what to say, so they said nothing at all.

But that silence was deafening.

I used to be the girl with the social life, the energy, the late-night dancing and the big dreams. Now? I’ve had to become the woman who measures every minute. Who mourns her reflection. Who’s learned how to smile while her body burns inside.

You grieve the old you. The gym-loving, brunch-going, multi-tasking version of yourself you didn’t realise was temporary. You try to live on adrenaline because you don’t want to admit it’s gone but it always catches up with you.

And eventually, you stop trying to chase who you were and start learning to honour who you are.

The healing that doesn’t happen in clinics

After the diagnosis came the paperwork, the politics, the endless appointments that led nowhere.

Then came the silence. My professor disappeared, his secretary stranded in Italy, the new NHS system “lost” me, funding requests vanished into the void. For a while, I wondered if the Prof had died.

Turns out I’d been misplaced.

So I took my healing into my own hands. I learned to ask different questions. I stopped waiting for a miracle and started building a livable life. I invested in reiki. Hypnotherapy. Holistic coaching. I even became a practitioner myself. Because if I was going to survive this mentally, emotionally, spiritually, I needed more than prescriptions. I needed meaning. I needed to be at the helm.

And slowly, something shifted. I stopped chasing up my consultant, co- ordinating my care with military precision that used my energy reserves up.

I stopped asking, “When will I be fixed?”

And started asking, “What makes me feel most alive right now?”

A different kind of success

Disability forces you to redefine what success looks like. No more chasing the to-do list like a religion. No more performing productivity for people who don't pay your bills.

Instead, you learn to prioritise peace.

You create a slower life. One with boundaries. One where rest isn't earned, it's essential.

You write again. You design. You build something of your own, not because you're chasing "the dream," but because the old dream doesn't work for a body that doesn't exist anymore.

And somehow, in between the grief and the flare-ups and the fights for treatment, you realise you're still here.

You're no longer buried, you've been planted and like all flowers you bloom in seasons just not all year.

Not just a month. Not just a flag.

Disability Pride Month started in the US in 1990 to mark the passing of the Americans with Disabilities Act. Now it's global. But like everything, the meaning isn't one-size-fits-all.

Some people feel proud of their identity as disabled. Others, like me, feel proud of how we've adapted, endured, and evolved.

Both are valid.

The updated Disability Pride Flag represents that beautifully. Five diagonal stripes, each a bold colour on a charcoal background. Each representing a different form of disability: physical, neurodivergent, invisible, mental health, and sensory.

The stripes are diagonal for a reason. They symbolise how we climb, navigate, and move through barriers, not because they're gone, but because we find a way.

The charcoal backdrop? It represents anger, grief, and remembrance. Because too many lives have been lost to a system that doesn't care until it's too late.

Nothing truly fits neatly into an awareness campaign.

My version of pride

I'm not proud of being disabled.

But I'm proud of all the times I showed up anyway.

I'm proud of the work I've done that no one saw.

I’m proud of the resilience I never asked to develop.

I’m proud of the way I’ve redesigned my life around truth, not pretense.

This isn’t just about July.

It’s about remembering that pride doesn’t have to look loud or polished. Sometimes, pride is quiet. Sometimes it’s getting out of bed when you didn’t think you could. Sometimes, it’s writing this when your hands ache and your brain is foggy, because someone out there might need to hear it.

And if you’re reading this maybe that someone is you.

Pride, Redefined

So no, I’m not proud of being disabled. But I’m not ashamed either.

I’m proud of the way I’ve rebuilt a life no one understands or approves of. Proud of the boundaries that protect my precious energy. Proud of the version of me that takes no shit.

I’m proud of the days I made it to the garden.

The days I laughed, even when it hurt. The days I choose gentleness over performance. And the days I said no without explaining.

This body has lost jobs, friendships, confidence and certainty. It’s changed shape, slowed down, it aches!

It’s not brave or broken. It is what it is.

And I’ve learned how to live in it.

I don’t need a flag to tell you that matters.

I don’t want anyone’s approval or applause.

I just want people to stop looking confused when I say I’m too tired to leave the house.

Disability Pride for me isn’t about identity.

It’s about compassion. And dropping judgment.

To stop proving. To stop explaining. To stop waiting to be believed. And if that makes someone uncomfortable, they can look away.

I’m not a victim in this story. And I’m certainly not special.

We all deserve to exist without being questioned.

That’s my version of pride.

It doesn’t come with a flag. It doesn’t need a hashtag. It’s not for show. It’s the next chapter of my story.

It’s not the life I dreamed of, but I’m here breathing and sitting in the sunshine, writing this, full of gratitude and safe in the deeper knowing when life throws me lemons, I am the lemonade.

If you’re still reading this, thank you.

This is what Disability Pride feels like, for me.

A final challenge

If you’ve ever rolled your eyes at someone for canceling last minute, questioned a colleague’s sick leave, or quietly decided someone was exaggerating because they looked “fine,” ask yourself this:

What makes you so sure you’d survive what they’re managing in silence?

Disability doesn’t always come with crutches or wheelchairs.

Sometimes it comes dressed for work, smiling, on three hours sleep, with painkillers in the bag and a breakdown on pause.

If you don’t understand it, that’s okay.

But dismissing it? That’s on you.

This Disability Pride Month, do better.

Start by believing us the first time.

Rachael

Editor-in-cheif EmpowHER

Founder Lemon Aid Coaching & Consulting

Nehal Just up to here - I’m finding some photos to add

When life gives you
Lemons

My very personal musings -
for an article in July's EmpowHER

Lemonaiding
Leadership
done differently

Disability
Pride

"But you don't look sick"

"But you don't look sick"

"What am I supposed to look like?"

When life gives you Lemons

“But you don’t look sick”

Disability Pride

This one’s my personal musings - for an article in July’s EmpowHER

Lemonaiding Leadership done differently

Join over 2877 healthcare professionals and subscribe to EmpowHER

Each issue is raw, unfiltered, and impossible to ignore. It's packed with voices that refuse to shrink and stories that demand space.

Change is the only constant, you can lead or you can follow!

For my LinkedIn post

You're not dead yet. But you're not really living either.

Your brain still works like that 21-year-old hot shot at uni. But your body has other plans.

You're often exhausted. 4 hours sleep is a pipe dream. Your reflection stops looking like you.

You slap on makeup like an artist. You've mastered looking human versus scary 🧟‍♀️

The gym, the walks, the spontaneous plans, all gone. You fall off the radar. People don't know what to say, so they say nothing.

Living on adrenaline 24/7 isn't the buzz people think it is.

You know people don't believe you.

If they can't see it, it's not real, right?

So you focus on what you can do.

You get intentional with your time.

You cut the mood-hoovers.

You protect your energy like it's gold.

You're still in there. The humour. The intuition. The warmth.

Some people see it. Some don't.

Their loss.

That's it. That's the lesson.

Miss Lemon's musings, for Disability Pride Month.

Read the raw version in July's EmpowHER 💜🍋

This is for all my other chronic illnesses warriors 💪🏻

Reworked article for later: May 2024

You're not dead yet. But you're not really living either

It's mental health awareness month and as a writer I thought I'd share some personal reflections

Living with a chronic incurable condition kind of sucks on so many levels

Your brain stills works as if your 21 years old, that hot shot geek at uni,

but your body has a different game plan!

Your always exhausted but the endless pain means you rarely sleep 💤

Subsequently your body changes and not for the better,

Your reflection on the outside doesn't mirror the inner soul you carry

You mourn the fun loving outgoing person that you can't even remember if that version was real or a figment of your imagination.

The little things you take for granted (the gym, lunches, walks for hours) fade as your disease progresses and your body degenerates.

The days of partying and weekend benders long gone, the physical toll and price too much, eventually you fall of your friends radar (maybe your miserable and don't realise but whatever reason they stop calling, invitations dry up) essentially your an avatar in your own story.

The living on adrenaline 24/7 isn't the buzz you might think!

You know people think you're making it up, if they can't see it - it's not real right!

Maybe you're crazy - that helps people rationalise your disappearance, or maybe you no longer serve a purpose.

Your on the outside looking in, wondering if somehow you offended people without knowing or you just bore them to death ☠️

You reach out and ask because you would never intentionally hurt a soul especially your "friends" you think they know your still you but maybe your just too boring or a burden.

Worse still a reminder it could happen to them, one day you wake up and your life is changed in the blink of an eye no going back.

Sometimes you slap on makeup, look halfway human, you're adept at concealing pain.

You're not dead yet but not fully living either,

You focus on what you can do, what's in your control, how you make an impact and writing your next chapter!

It's equally as liberating because you evaluate who and what you spend your useable hours on.

No more accepting shitty behaviour or people who don't truly value what you have to offer the world - mood hoovers, people who drain you are eliminated.

Inside you're still the same person, with a wicked sense of humour, razor sharp intuition and kindness in abundance.

You show up with gratitude each day for the little things that light you up and the people that ignore you - you know deep down it's their loss!

After the grief comes acceptance and you find an inner peace and contentment, thankful for the people who chose to stay and the ones that left to make space for better humans to remind you life can be equally as beautiful as it is cruel.

And if you do care about someone tell them often.

That’s it that’s the lesson, Miss Lemon’s musings on this journey we call life!

Miss Lemon’s Mental Health Musings: You’re Not Dead, But You’re Not Really Living Either

Living with a chronic, incurable condition?

It’s not just exhausting. It’s identity theft.

Your brain still fires like that 21-year-old hotshot from uni—top of the class, razor-sharp, full of fire.

But your body?

It didn’t get the memo.

You’re drained before the day begins.

You don’t sleep—not really. Pain doesn’t rest.

And your reflection? It doesn’t look like you anymore.

The sparkly, outgoing version of you feels like a rumour. Were you ever really that girl? Or was she a short-lived dream from a body that had no intention of lasting the course?

The gym sessions. The dancing. The spontaneous weekends.

Gone.

Not because you changed. Because your body stopped playing ball.

People drift. Friends disappear.

At first, the invitations slow. Then they stop.

Eventually, you become an avatar in your own story—still here, but not really seen.

And you start to question yourself.

Maybe I am too much.

Too boring.

Too sad.

Too sick.

Maybe I make people uncomfortable.

Maybe I remind them that life can change in a blink. That health isn’t promised.

Maybe I’m just too real.

So you disappear quietly—except on the days you force yourself back into the world, full face of makeup, bright smile, scripted lines ready.

You get good at hiding.

Pain becomes performance.

But inside, you’re still that wild, intuitive, kind soul with a wicked sense of humour and a brain that refuses to quit.

You’re not dead yet, but you’re not fully living either.

And that’s the part nobody talks about.

Because being alive isn’t the same as feeling human.

But here’s where it turns.

Chronic illness gives you a brutal gift: clarity.

You learn to spend your useable hours wisely.

You stop tolerating half-hearted friendships and mood-hoover energy.

You let the wrong people go—without apology.

You find peace, not in healing, but in honesty.

You become proud—not of your condition, but of how you survive it.

You stop chasing the version of you that once was…

And start building a version that fits the now.

You get ruthless with your boundaries.

You write your own next chapter.

You make space for the new. The true. The nourishing.

And slowly, something strange happens:

Life softens.

Joy returns—in moments, not milestones.

You feel love in the small things.

And you realise the people who stayed weren't just kind—they were brave enough to witness your truth.

So if you care about someone—tell them.

Often.

That's it. That's the whole lesson.

And if no one's told you today:

You're not a burden.

You're not broken.

And you still matter—exactly as you are.