

OWNING IT

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Dear reader,

This is the book we wish we'd had when we were young.

As disabled children, we didn't see many people like us in the books we read or the films we watched. And, when we did, we usually wished we hadn't! If they were the good guys, they were inspirational people whose disability was their 'superpower'. If they were the bad guys, their disability was part of their evilness – like Captain Hook – which was annoying. And boring.

Because, really, disability isn't like that, is it? Disability is a normal part of everyday life. Did you know that about a quarter of people are disabled?¹ That's a lot of people! And we think books and films should show that, too: how normal it is to be disabled.

Perhaps you are disabled yourself, or you know someone who is? You probably know someone who will be, one day. Some people are born disabled, and some become disabled later in life. Of the three of us editing this book, two of us – James and Jen – were born disabled, and one of us – Lucy – became disabled later.

¹ According to UK government disability statistics, published August 2023.

There are so many ways of being disabled, and so many ways of feeling about it, too. That's something we wanted to show and celebrate in this book. Each chapter is written by a different writer, and each writer was once a disabled child. This book is not a perfect cross section of the disabled community, though we did our best to find writers with as wide a range of disabilities and backgrounds as possible.²

We asked these writers to tell us about a memory from their childhood – something joyful or challenging or funny. In this book, you're going to read about Jan skating across the Norwegian ice in his wheelchair, Matilda stargazing with her mum in Nigeria, and James leaving his leg at home (yes, really!). However, while people have such different bodies and lead such different lives, the things they need and want and wish for are often similar, so this book celebrates that as well.

We can't change our disabilities. But we can own them. That's what the title of this book means. If you're disabled and you don't feel like you're owning it right now, that's OK. Hang in there. Growing up with a disability isn't easy, sometimes because of our own

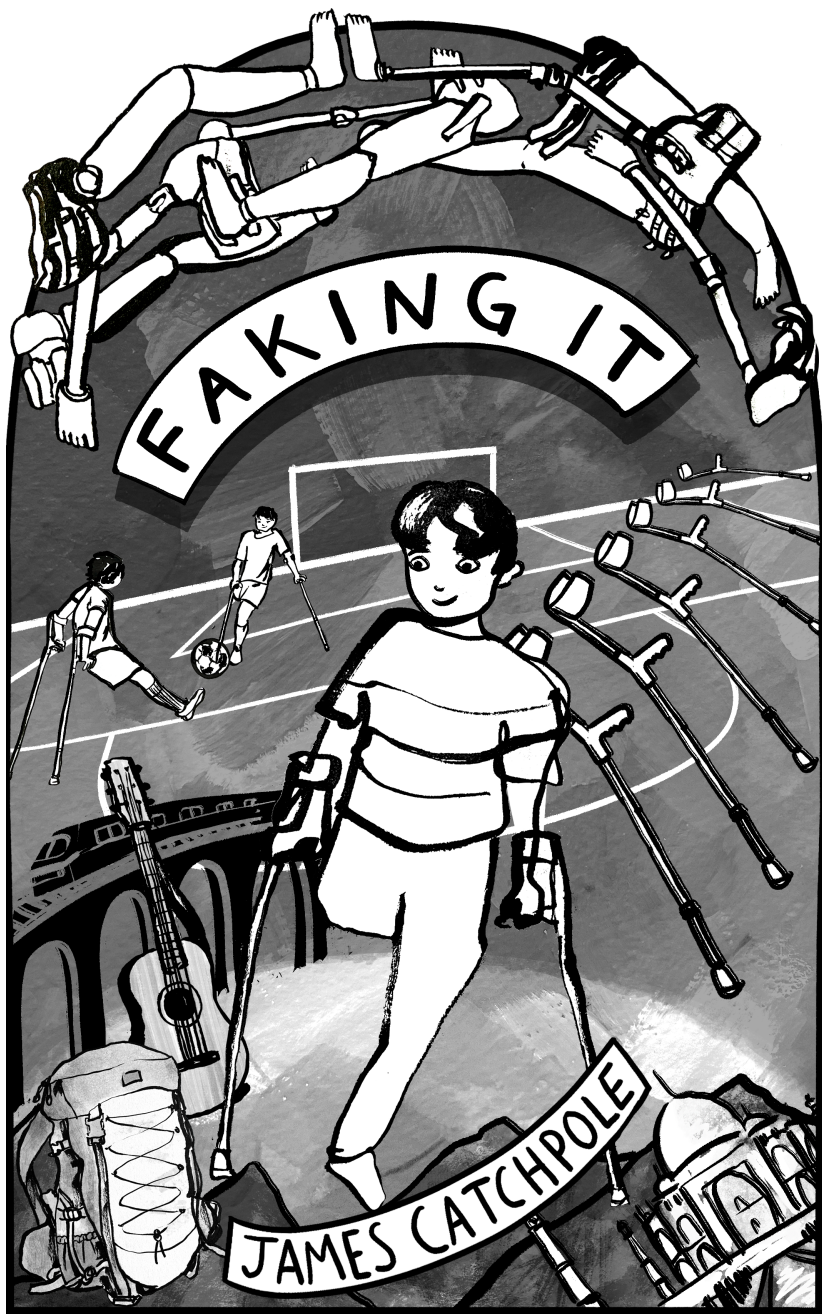
2 We work as writers and publishing people in the UK, and we've reached out to writers, first and foremost. Our pool of contributors cannot help but reflect this.

bodies and sometimes because of the world around us. Many of us were made to feel ashamed of our disabilities when we were young. Many of us weren't given the words to talk about that part of ourselves, so we could be proud to be disabled and find strength in our togetherness.

Our hope is that you find the strength and the pride and the words you need. Some of them might even be in this book.

All our love,

Jen, James and Lucy



Faking It

by James Catchpole

United Kingdom

People always want to know what happened to my leg. They did when I was a kid, and they still do now that I'm forty-something. So I'm going to tell you.

It's a good story. Ready?

My leg never really felt like part of me, and this feeling grew over time, so that, by the end of primary school, I'd started to feel I'd be better off without it. And soon after I started secondary school, I knew it was time for action. So, off came the leg.

My parents were a little anxious, it must be said. They worried for my health. But I reckoned it was my decision at that point – I was thirteen after all – and they couldn't really stop me. I just did it myself one morning before school: I left my leg there, on the bedroom floor, and off I went.

Best decision I ever made.

I hope you've worked out by now that I'm talking about

my fake leg. If not, then that last scene must have looked kind of dramatic in your head. Was it . . . messy? Sorry. I can tell you now, no home-surgery involved. No one had to shampoo the carpet.

The leg I ditched at thirteen was the false one. That's what we called it: my false leg. And that's how it felt to me, by that stage: like a fake. A counterfeit.

I'm a single-leg, through-hip amp – pretty much always have been. The first part of that is medical-speak for 'one leg, all off'; the last part is amp-speak for 'amputee'. And 'amputee' just means you're down a leg or arm, or two.

As a leg amputee, from the time I could stand up, I'd been given a prosthesis – a false leg – to walk on. If that brings to mind those dashing Paralympians, charging round a running track on futuristic blades, then do by all means enjoy that thought. I do. Those guys are excellent. But that was never an option, and not just because it was A Long Time Ago.

To run with a blade, you need part of a real leg to attach it to. Just a few inches of leg will do. But being a through-hip amp means there's nothing below your bum. And you can't attach a running blade to your bum.

Well, you probably can, but not in any useful way. No, a through-hip prosthesis doesn't really conjure the word 'dashing'. It's a modified bucket-and-stick job. You sit in the bucket and walk on the stick. I say 'walk', but it's more of a lurch, really – you know, like Lurch, from *The Addams Family*.

To be fair to the prosthetists, they did their best and the modifications were clever. There was a rubbery foot-shaped foot to give you some balance and spring. And there were joints: a 'free hip' to allow the leg to swing forwards independently of the rest of you, which did make things just a little less lurchy; and for the very daring, a 'free knee', 'for the smoothest, most natural walk'.

I liked the idea of a free knee, because it rhymed, which made it sound like a political slogan, and who doesn't like the idea of freedom, even for knees, which work so hard after all. But I never mastered it. There was a price to be paid for walking more smoothly. To walk with a free knee, you needed to walk slowly and evenly. And what kid wants to walk slowly and evenly? I tried rushing and collapsing for a bit, then gave up on the free knee, and went back to rushing and lurching. Sorry, knee.

You may not know this, but they weigh a bit, through-

hip false legs. Especially grown-up ones. These days, if I leave mine standing in front of the snack cupboard, my youngest daughter can just about drag it clear so she can reach her crisps after nursery. She's almost four, though, and powered by crisp-lust. A year ago when she tried moving my leg, she tended to get squished.

When I was little, like her, I don't remember the leg feeling heavy. I used to rush around the playground on it happily enough. The action must have been a kind of rapid lurching – a tiny, utterly unselfconscious gallop. In fact, I can remember demonstrating my fastest gallop to the class at six or seven, and charging headlong into a stack of chairs.

There's a report from the headmaster of the school I joined at eight, which says much the same. He's reassuring my parents that I'm 'tearing around the playground' with everyone else. And I think that was true enough.

By the time I finished at that school five years later, I wasn't tearing around, though. They make bigger legs for you as you grow, and the proportions stay the same. But somehow, what felt easy enough at eight no longer felt so easy at twelve. By then, I'd started to feel the leg was a weight I was dragging along with me – like an

anchor. I can't say why, exactly, but as I got bigger, the lurching got slower and harder – and sorer, too.

I'd also become more aware of how different my false leg made me from everybody else. Having one leg wasn't a problem. Funnily enough, I'd always been fine with that. No, it was the false leg that was giving me doubts. It was hard to see at the time, but we'd grown apart, the leg and I. We just wanted different things. And frankly, I'd started to question its worldview.

Because here's the other thing, besides the weight and the lurching. My false leg had impossible dreams. It wanted to be a real leg. You could tell, because they'd covered the stick bit in squishy, flesh-coloured foam and sculpted it in the shape of a real leg. It looked like they'd hacked a leg off some kid and stuffed it in one half of my posh granny's tights. They'd covered the bucket bit in thin, flesh-coloured rubber, too, and that just looked, well, like half a bum. With air holes.

I wasn't buying it. Nobody was going to see me in my pants and say, 'Why, that kid has two almost-identical legs! And he's wearing tights! But only on one of them! And he appears to have airholes drilled across half of his bum . . . But other than that, identical!'

Nevertheless, my false leg **was** supposed to pass as a real leg. It was designed not to be seen, but to be hidden. It was supposed to be worn under clothes. The sculpted foam was there to nicely fill a trouser. The flesh colour was in case I wanted to wear shorts, I suppose (or flash my bum at someone **very quickly**). And as long as I put it on every morning, preferably under long trousers, and walked with it slowly and evenly, on a free knee, and didn't take it off until I was home again, then no one would need to know the awful truth of my one-leggedness.

And what a relief that would be! Not just for me, you understand, but for anyone who might have been disturbed or discomfited by the sight of me . . .

I should say, no one gave me that message explicitly – not that I remember, anyway – but that was the message that seemed to be implied by the whole process of limb-fitting: **you'll probably want to hide that as best you can, so as to fit in.**

Maybe I shouldn't be surprised by this. My false leg was being fitted in the 1980s – a time as close to the Second World War as it is to now. In fact, the man who made my first legs had looked after fighter-pilot ace Douglas Bader, who had famously fought the Nazis on a pair

of falsies. You can see him in the biopic *Reach for the Sky*, learning to walk again after his flying accident, all glorious stiff upper lip and pipe smoke.

I imagine a dignified lurch and a walking stick were quite the badge of honour back then, along with military medals and marrying your nurse. But what I was finding, forty years on, was that false legs that pretended to be real legs just confused people.

I still got the questions, like, 'Why do you walk funny?' But when I told the other kids, 'It's a false leg,' they tended to feel, well, tricked. Either they believed me, and realised I'd been tricking them into thinking I had two normal legs, or they thought I was **still** tricking them by **pretending** one of my legs was fake. I have a memory of keeping a set of compasses in my pocket – they had a sharp steel tip for digging into paper – so that I could make a show of stabbing my right leg, just to convince people it was fake: one conjuring trick to disprove another!

The trickiest thing about the trick, though, is that you can end up accepting the idea behind it: that it's best for everyone – for you and for others – if you don't show anyone who you really are. And that idea leads to **all kinds** of difficulties.

What about school sports? All week, you drag this leg-shaped anchor around, this conjuring trick to hide your difference. And then twice a week, when sport comes along, you go into a changing room with all the other kids in your class and pull back the curtain to let daylight in on the magic. Well, actually it's a little more awkward than pulling back a curtain:

1. Belt open, trousers down to knees to reveal socket.
2. Undo Velcro straps around socket, ease bum out of socket and sit down, leaving leg standing.
3. Take shoe and trouser leg off real leg, pull trousers back over false leg and lean it against bench. Then for sports involving the leg . . .
4. Turn the leg upside down and lever the shoe off (with a 'shoehorn' where needed), before undressing it and redressing it in shorts and a sports shoe.
5. Put shorts over real foot, add sporting footwear, stand up, re-attach leg, pull up shorts.

Needless to say, all the other kids are out on the sports pitch already, and by the time you've trudged out there on the leg, the lesson is mercifully half-done.

For sports where the leg would get in the way (like gymnastics) or drown you (like swimming), getting changed is a little quicker – you can stop after Step 3. But then you have to step out of the changing room as your true, one-legged self in the full light of day . . . So what was the point in faking it the rest of the time?

I was very lucky with my school: no one teased me. Well, one kid did, just once, and only in passing in an exploratory kind of way. And I immediately did what I'd been trained to do, which was to tell my mum, who told our neighbour, who told her son who was massive and into rugby. And I'm pretty sure he must have thumped that kid, because the sight of me made him noticeably anxious after that. But even though no one bullied me (and I know now how unusual that is), I still felt like I was revealing a shameful secret whenever I had to take off the leg. I still felt intensely vulnerable, every time.

Then, as I got older, another way of being presented itself.

I haven't mentioned crutches, have I?

Crutches are **the best**. If you're missing the whole of one leg, which of these sounds more natural? Either you can strap a fake leg around your bum with Velcro and learn to balance on it, and then, slowly, to lurch. Or you can

use the limbs you do have to do the job of the one you don't: you can use crutches to walk with your arms.

When I got home from school, exhausted from dragging my false leg around all day, and more likely than not rubbed raw from the socket, I'd take off my leg and pick up my crutches. And what a relief that was! Crutches may sound like hard work, but if you use them every day your body soon adapts. Your arms and shoulders muscle up until they can easily carry your weight, and the skin on your palms toughens: pretty soon your shoulders stop aching and your hands stop blistering, and then crutches are just how you walk. Or run . . .

By the end of primary school, I was nimble and quick on my sticks, in a way I never could be on my leg. The problem was that I wasn't supposed to use crutches. The doctors and the prosthetists had communicated to my parents that crutches were just a way of avoiding using the leg, and that we amputees **had** to use the leg for our long-term good. Who knows what problems crutches would cause for our bodies as we grew? It was supposed to be obvious that wearing a fake leg – dressed up as a real leg – was the natural, sensible thing to do.

Well, maybe. Although . . . the part of the body that the false leg attaches to isn't **necessarily** longing to be part

of a leg again – it feels no urgent desire to be walked on (not in my case, anyway). Sewn-up flesh and severed nerves and bones aren't always thrilled at the prospect of weight-bearing and being pounded into a pulp inside a socket. And though legs may have been designed for walking, arms can adapt to the task pretty well, if they're healthy and whole. But that's not an argument I could have found words for, even if I'd known the truth of it when I was a kid.

So, wearing crutches instead of the leg at school had to be an act of rebellion. No one seemed to think it was a good idea, and I couldn't have just decided to do it unprompted. I would have felt like I was going against the wishes of my parents, and in some odd way, betraying the prosthetists who knew what was best for me . . .

It had to start by accident, then.

I think the first step was at a birthday party on a weekend. Maybe I was ten or eleven. There was a game of football in a sports hall, with a soft, indoor ball. I'd have been on crutches because there were trampolines, too, and trampolining with a through-hip prosthesis was a recipe for pancaking your vertebrae. Anyway, I was on crutches, and I took an experimental swing at the

ball. Reader, I toe-poked it straight into the top corner. And as far as I can remember, that was it: my eureka moment.

The next step was seeing a football competition advertised at the school summer fete: '£5 if you can score a penalty kick against a teacher!' I made a plan to go on crutches, without my false leg.

The plan grew in my mind. Each penalty taker would get five kicks. Despite having been virtually unable to kick a football on my leg and having been an awkward bystander at every school football lesson ever, I was fairly sure that on crutches I'd score all of them. That would be £25, thank you very much. I pored over the toys section in the Argos catalogue to see what my winnings would get me.

When the moment came, things did not go as planned. Again, none of the other kids teased me. I think they were curious – maybe even impressed. It's just that they were all watching – of course they were! – and I realised, as soon as I took my first kick, that I'd never tried to kick a real football before.

This real ball was far heavier than the soft, indoor one. The most I could do was to send it rolling gently

towards the goal. On my fifth and final kick, which was meandering harmlessly wide of the post, some older kid sitting next to the goal popped the ball into the net and everyone cheered. I remember cringing with embarrassment, but it probably helped us all out of what must have been an awkward situation. At that point, a supportive laugh and a 'well done for having a go' were about the best I could hope for. Perhaps my false leg was grinning to itself, back home on my bedroom floor: 'And you think I have impossible dreams?'

The football had been a humiliation, but still, something had been accomplished. I'd stood up in front of what had felt like the whole school, as myself. No tricks, no secrets, no trying to fit in – just me with my trouser leg hitched up, standing there on my one leg and my crutches. The genie was out of the bottle.

It was another year or two before I finally split with the leg, but I can remember my sense of relief when I did. And I felt no shame. No vulnerability, either. What I felt, was utter, unshakeable confidence. No more dragging my anchor with me. No more climbing the stairs one slow step at a time. No more being left behind to go at my own pace. No more staying in the classroom at break time, because the lurch to the lunch hall felt too far.

Honestly, it felt like flying.

Instead of dreading every journey between classrooms, I relished them. Now I was going to travel with panache. The doors had metal kickplates at the bottom to protect the wood – I kicked them open without breaking stride, so that they slammed back against the walls as I passed. What teacher could protest?! I didn't walk up the stairs, I ran. They go more easily with a little momentum behind you in any case, but to go from one step at a time to two or three . . . Odd for a staircase or a door to be a thing of joy, but for me they were. The sudden joy you feel with freedom.

For a decade after that, I hardly touched the leg.

I started playing football properly on crutches with my friends at weekends. We bought train tickets round Europe after we finished school, and juggled our football through Milan and Venice and Barcelona and Prague. I remember running up the hundreds of steps at Montmartre in Paris without breaking too much of a sweat.

I learned to sing and play the guitar so that I could busk and hitchhike my way round the South of France, at first with a friend and then on my own. Having one leg proved

to be a bonus for both of those. To my surprise and relief, it didn't seem to be any kind of disadvantage with girls, either – in fact, it seemed to have the effect of signalling hidden depths of character, whether real or otherwise!

I took a gap year and travelled solo around India. My parents seemed to have warmed to the idea of crutches by this time as they just seemed proud of me, though perhaps it was more relief that I'd come home again (this was just before mobile phones came along, and I only called them every few weeks to let them know I was still alive).

I did take my leg to university, but for one reason only. On Thursdays I would run from my college, on my crutches, right across to the sports centre on the other side of town, where my leg lived in a locker. I'd strap it on for two hours of badminton, then cram it back in the locker and run all the way back to the college bar in time for last pints. And if that's still not super-crippy enough, there's more: I briefly played football for England (international amputee football on crutches – it's a thing). I was always rubbish at penalties, though.

The inspirational spiel isn't the point, though. The point is this: none of it was pre-ordained. I could have stayed on my fake leg. I could have learned to use a free knee

and maybe passed as two-legged. I could have walked slowly and evenly through my teens and early twenties looking more-or-less normal. I still wonder how different my life would have been.

Then again, how would my life have been had I worked this all out sooner? I should have been playing football every lunch break from when I started primary school. I'd have played a lot more times for England if I had! But I'm just so relieved that I worked it out when I did. Because once you buy into that idea of hiding your disability and fitting in, it's hard to let go of it. And if you don't let go of it, what might you miss?

Now, I use my leg every day. My robot leg is a tool. It doesn't dream of being a real leg. It has a scuffed old rubbery foot for balance (bare – no shoe), a steel shaft with a fixed knee, and a black socket that always seems to be covered in unicorn stickers. It straps on outside of my clothes, so I can take it off whenever I want, and I wear it to free my hands. I have two small girls to feed and tidy up after, and my wife uses a wheelchair, so my hands are needed.

But I leave the leg at home when I go out. For outside, I have a pair of beautiful black titanium crutches, made just for me.