

# Graham Findlay

## Keep on keeping on

*Like many of you, I was formally diagnosed with dystonia (early-onset generalised variety) late in the day – in my case about thirty years after my symptoms first appeared as a seven year old child. Having gone through a wide range of treatments, starting with organic seaweed baths and journeying through biofeedback, hypnotherapy, and a bathroom cabinet full of drugs – I finally arrived at botulinum toxin as the therapy of choice.*

I'm married to Julie, a counsellor, and have three children, aged 14, 19 and 22. I remember being told by my doctors that dystonia wasn't inherited. But in fact two of my kids have since developed the condition. The other has autism.

So – three of us in the same family with dystonia. And yet I can't detect any signs of dystonia in any of my immediate or distant family members – we've been singled out for special treatment. How do I feel about all this? Well, I can't deny pangs of parental guilt about giving my children this not-very-welcome gift that keeps on taking, but I know that guilt is not a particularly useful emotion so I try to keep a lid on it. My kids need my positive support and advice when I can give it (not that they always take it!) and possibly even a role model – though don't tell them that as they'll probably laugh.

I'm fortunate that I 'discovered' the social model of disability in my twenties. This is the wonderful idea that disability is mainly about the barriers that society creates that prevent disabled people participating in it, rather than being a personal tragedy. The positive aspect of this is that you can start to tackle and dismantle the barriers – things like discrimination, inaccessible environments, prejudice and harassment. It also instills a sense of pride in being who you are – your identity as a disabled person. In my case, I began to stop feeling ashamed, guilty and blaming myself for my dystonia, and started working in the disability rights sector to change things for the better for all disabled people.

As the disability trainer Simon Minty says, "Difference is the one true thing we all have in common."

I've worked for over 15 years in disability-related work in the third sector. I've naturally had some difficult moments, including discrimination at interviews, patronising comments and attitudes from non-disabled colleagues and sadly from some disabled people themselves, and have faced up to them and challenged them. My speciality has until recently been policy work and campaigning, which involved meeting and debating with influential, senior officials – the great and the good, including government ministers. So I had to develop an assertiveness and confidence when dealing with them, and make my dystonia an asset. Public speaking was, and still is, anxiety-inducing, but I try to get stuck in and get on with it. I'm a firm believer that we need to speak for ourselves, and that disabled people need to be seen on the public stage, talking about the issues that are important to us. Nothing about us, without us, I say. Moving to a management job in the 'mainstream' sector with a national housing organisation was a daunting prospect – but was one of the best moves I made. I now recruit disabled people to become trainee housing professionals and mentor them to become leaders in the sector – really rewarding work, which is a testament to that rare beast, a disability-aware and supportive employer.

I hope my children will be able to have a rewarding career of some kind too – my daughter has just clinched a job as disability officer for her students union so a chip off the old block – and I am optimistic that there is less discrimination than when I started working, but we do still have a long way to go. We need to keep re-asserting our rights as disabled people to live and work in the same way as everyone else. As the great, late singer and civil rights activist Curtis Mayfield said, just keep on keeping on.

The charity RADAR has recently published a useful guide, *Doing Careers Differently* aimed at disabled people. Their web address is: [www.radar.org.uk/publications/doing-careers-differently/](http://www.radar.org.uk/publications/doing-careers-differently/)



● Graham and his son