

# No time for the final straw, I'm too busy

## THE MOTOR NEURONE DIARIES

GORDON AIKMAN



### THURSDAY, NOVEMBER 10

Gin and tonic, please." The woman pushing the trolley seems surprised. There are many things I cannot do, but drinking gin is not one of them: a marvellous invention, the drinking straw, makes all sorts possible.

Four-and-a-half hours of chuntering down the east coast later, we arrive. It is a trip I have taken countless times before. This time I require adult supervision – I am travelling with my carer.

Be it plane or train, if you are in a wheelchair you are always last off. A fold-out metal ramp delivers me from carriage to platform. At big stations like King's Cross the operation tends to be slick. There are plenty of people around to help. Plenty of others get in the way. Every wall screams "Keep left", but in London – the city of sharp elbows – the best tactic for beating crowds is speed. It is incredible how quickly people move when a wheelchair is hurtling towards their legs.

### WEDNESDAY, NOVEMBER 16

I am back in Edinburgh planning a very different trip: popping round to see a friend. She lives just a 20-minute walk away, but having never done the trip solo, I am nervous. It must be bookended by time with my carers, so they can help me get my jacket on and off. My window is from 12-2pm. As I set off, I share my GPS location on my mobile so my friend knows if and when she need worry.

It feels like an adventure and bizarrely exhilarating. The whole time

I am telling myself: "I am doing this, I am really doing this, look at me go!"

With carers visiting six times a day I am rarely on my own, so when I am it is hard not to feel vulnerable. I am easy prey for anybody who wants a battered iPhone or rucksack full of straws. At any point I could hit something and catapult myself out of my wheelchair. The most ordinary of pursuits feels like the biggest of challenges. I am relearning how to live life.

Victory! I make it there and back, with a lovely lunch and catch-up in between.

### SATURDAY, NOVEMBER 19

An email lands. It is from Michael Ball. He is on tour with Alfie Boe.

Michael – thoughtful and generous as ever – invites us along to his Glasgow gig next Saturday. Ever since he and his partner Cathy heard me talking about my campaign on LBC radio, they have been hugely supportive.

### MONDAY, NOVEMBER 21

I catch up with Judy, Scotland's lead MND nurse. With our campaign promise to double the number of nurses now a reality, the new enlarged team are making progress. Smaller caseloads mean nurses can spend less time driving miles between patients, and more time delivering quality care. Another indicator of success is the record high membership of the Scottish MND patient register. As the breadth and depth of information increases, the more attractive Scotland becomes as a place to host clinical trials.

With as yet no cure for MND, trials are what it is all about: trials offer hope.

### THURSDAY, NOVEMBER 24

"Are you still collecting for your charity?" asks my taxi driver. I nod, "Yes, I...", and before I get a chance to tell him about the next big fundraiser, £5 is thrust into my hand.

"Wow! Thank you." I hesitate. "In fact, can you put it in my pocket for me?" It is blowing a gale, I am not going to trust these clawed hands. He



Michael Ball has been a great supporter

obliges. His donation takes my fundraising total to £520,884.

### SATURDAY, NOVEMBER 26 (MORNING)

I am up at 6.30am to get through to Glasgow in time for an MND Scotland board of trustees meeting. It is a long but productive session. The early start – travelling and then the meeting itself – takes it out of me. I could stay at home and conserve my energy, but I think it is vital that at least one patient sits on the board at all times to keep the charity focused on those it seeks to serve. From now on that will always be the case, after the charity backed my proposal.

### SATURDAY, NOVEMBER 26 (EVENING)

"I am sure it is in there somewhere, keep looking!" It is minutes before the show starts. And no, it would appear that I do not have my special "radar" key that opens disabled toilet doors. Sunglasses, umbrella, straws, painkillers, two bottles of water, more straws but no key.

The contents of my bag are strewn across my lap and the floor. Joe runs to ask a steward to open the door. Thankfully I was not desperate! We squeeze ourselves in to the tiny loo. Relieved, I exhale. We hear the band starting up. "We are missing the first song!" I move to let Joe into the sink,

setting off the hand dryer: we both get blasted. We laugh. It is like a crap slapstick routine.

In the theatre, Ball and Boe are a tour de force. Add to that their charm, onstage antics, rapport with the capacity crowd and boundless energy – the show is an utter joy.

### MONDAY, NOVEMBER 28

Splat! My white T-shirt now has a tomato-coloured splodge. As the muscles in my neck weaken, I am doing my involuntary Churchill dog impression increasingly often.

Without notice, my neck flops forward, chin to chest. It is a frustrating reminder that MND is progressive. I have been given various support collars to try, but for now they remain in a drawer. It is daft I know: they would help, but it is another chunk of autonomy I am not yet ready to give up. For now, I will opt for a costume change and an extra load of washing.

### TUESDAY, NOVEMBER 29

I am in Leith celebrating the third birthday of Euan's Guide, the disabled access review website and app. Founded in 2013 by Euan and Kiki MacDonald, after Euan became a powerchair user, the site boasts reviews of 5,000 venues across 30 countries.

There are drinks and nibbles, but my mind is in overdrive. When I see Euan I always wonder if I am seeing my future self. Euan has become a great friend. He, like me, studied at Edinburgh University. We both live near each other in the capital. And, we were both diagnosed with MND at 29. There is much we have in common. But he, unlike me, breathes using a tracheostomy and, having lost his voice, speaks through a computer controlled by his eyes. As my breathing deteriorates and my voice weakens these are two difficult decisions I will need to take. But not quite yet.

*Gordon Aikman is a Motor Neurone Disease patient and campaigner. To donate to his campaign to fund research into a cure for MND text MNDS85 £5 to 70070 or visit [GordonsFightback.com](http://GordonsFightback.com)*