

THE BIG READ GORDON AIKMAN ON HIS DETERMINATION TO HELP SUFFERERS AND FIND CURE



SUPPORT Former prime minister Gordon Brown is backing Gordon's campaign

"YOU been in the wars, son?" asks the security guy as I hobble through the metal detector at Edinburgh Airport, setting off the alarm."

You could say that, I reply under my breath. "It's Motor Neurone Disease." He frowns, confused, holding my gaze, then his face lights up: "Ah. The Ice Bucket Challenge disease."

I smile: "Exactly."

The Ice Bucket Challenge took the world by storm this summer. Even at the most tense and vicious stages of the independence referendum battle, campaigners from both sides paused to drench each other with freezing water.

Alongside Better Together colleagues, I picked up a bucket to soak Alistair Darling – making a splash not just in Glasgow's Blythswood Square but in the Record too with the headline Wetter Together.

As well as raising more than \$100million for MND-related charities, it boosted awareness of this devastating illness. You can't put a price on publicity like that.

When I was diagnosed in June, like most people I didn't know much about Motor Neurone Disease (all I knew was that it sounded pretty awful). My consultant explained "it is rare, progressive and debilitating" and would "attack my brain and spinal cord".

There is no cure. The experts don't know what causes MND, never mind what they need to do to cure it. What we do know is it kills – and fast. Half die within 14 months of diagnosis.

Of course, doctors are keen to stress "everybody is different" and "it's difficult to predict". But you can do the maths. I'm 29. The chances are I won't see 31. This could be my last Christmas.

In the seven months since my diagnosis, MND has ravaged my body. I barely recognise it and the change is hard to bear. Just months ago I was lifting weights at the

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gym, now I struggle lifting the kettle. I've gone from a medal-winning gymnast to being overtaken by grannies on the street.

It will systematically weaken every muscle in my body until I am paralysed. There is no let-up. I now walk with a stick. And with each passing day I clutch it ever tighter. Even with a crutch I fall regularly – my knees are covered in cuts. Stairs are the enemy.

Doctors reckon I'm weeks from needing a wheelchair. I fear they are right. In time – in fact already – Motor Neurone Disease is affecting how I eat, drink and breathe.

You might think I'd be angry but I'm not – 2014 has been the best and worst year of my life. Yes, I've

been handed a death sentence but I have fought back. The clock might be ticking above my head but I refuse to give in. I'm determined to make the most of the time I have left.

On a personal level it has forced me to get my priorities in order. I've travelled more and spent more time with friends and family than ever. It shouldn't take a shock like this, but how many of us can hand on heart say their work-life balance is right?

And I've started Gordons Fightback.com, my campaign to improve care for people with MND and raise vital funds to find a cure. It wasn't until I was living and breathing it that I realised just how raw a deal patients get.

I want to make 2015 the year Scotland transforms care for people with MND and we make progress in funding a cure. We must:

● Pay MND nurses from the public purse. The nurses who provide the care and support I need are a lifeline. They have decades of experience. I don't know what I would do without them. But they only exist because of donations made to charity. It is ludicrous that people have to run

I want 2015 to be the year that Motor Neurone Disease care is transformed.. it's ludicrous folk have to hold bake sales and run marathons so that people like me can die with dignity

Campaigner explains why he refuses to give up in the face of devastating diagnosis



» I have met a lot of inspirational people this year but none more so than Gordon.
FIRST MINISTER NICOLA STURGEON

» Gordon Aikman's campaign is brave and passionate
SCOTTISH LABOUR LEADER JIM MURPHY



BATTLE Gordon and, top, with First Minister Nicola Sturgeon

TIMELINE

June 10, 2014

Gordon diagnosed with MND

July 14, 2014:

Gordon launches GordonsFightback.com

Jul-Aug 2014:

Ice Bucket Challenge sweeps the globe

Sept 3, 2014:

The Record's David Clegg referees as Yes and No campaigners unite against MND in charity penalty shootout

Nov 4, 2014:

Gordon is invited to No10 Downing Street by Samantha Cameron to celebrate the success of Gordon's Fightback

Nov 20, 2014:

Gordon win's Judges Award at Politician of the Year Awards

Nov 25, 2014:

Gordon meets First Minister to discuss campaign. Nicola Sturgeon agrees to review specialist nursing and outflow care charges if required.

Dec 11, 2014:

Gordon smashes £100k target, making him one of the top fundraisers in MND Scotland's history.

Gordon's FIGHTBACK

TO DONATE

Please TEXT "MNDSB5 £5" to 70070 or visit: JustGiving.com/GordonAikman. Thank you.

marathons and hold bake sales so people like me can die with dignity. These nurses are providing a vital public service, they should be paid for from the public purse.

● Double the number of MND nurses. There are more than 400 MND patients in Scotland and the number being diagnosed is increasing – yet there are just seven specialist nurses for the whole of country. That means far too much time is wasted getting to – instead of caring for – patients. Doubling the number of MND specialist nurses would revolutionise the quality of care for patients.

● Make charging terminally ill people for care illegal. In some parts of Scotland, MND patients are paying for the help they need with things like washing, dressing and

feeding themselves. When you are on your deathbed, the last thing you should be worrying about is money. Wishy-washy guidance that some councils ignore isn't enough – charging terminally ill patients needs to be made illegal.

● Fast-track benefits. People with MND do not live long – half die within 14 months of diagnosis. Yet it can take up to seven months to process applications for the benefits they need. During this time carers can't access the help they need either. The UK Government need to develop a fast-track system that means terminally ill patients and their carers get the support they need, when they need it.

● Finally – and most importantly – we must find a cure. That means investing in research like never before. So far, over 3000

people have donated to Gordon's Fightback, helping me smash my £100,000 target. That's amazing but I'm just getting started.

I know we can raise a lot more, that's why I'm raising my target to £250,000. Ahead of the 2015 General Election I'll be pressing all the parties to include a manifesto promise to double investment in MND research. Only by doing so can we find a cure quicker.

This has been a big year for me – and for MND. My life has changed forever but I would be lying if I said it was all bad. I have taken the fight to the top.

Our politicians say they are listening. Our challenge for 2015 is to make sure they deliver. Gordon Aikman is a former senior policy and communications adviser to the Scottish Labour Party and was director of research for Better Together. To find out more, visit GordonsFightback.com