

Parliamentary reception June 2015 - David Setters' speech

I am humbled to have been given the opportunity to speak today, in the presence of so many of you living with MND, caring for those with MND and volunteering and campaigning on our behalf.

I say "humbled" because I consider myself lucky to have a slowly progressive version of the disease. Many others experience a far more rapid and debilitating progression. There are sadly also many others who are much younger than myself.

For me the most difficult thing was telling Helen and my three sons about my diagnosis. That will remain forever etched in my memory. Thankfully, my children are in their mid to late 20s. I can't imagine how difficult it must be for those who have to explain it to younger children.

Specifically, I have the so-called "flail arm variant". Given the surroundings I would have loved to have done a Tony Blair or David Cameron impression today – you know, tie off with arms all embracing and fingers pointing – but sadly that won't be possible. And while I could describe in detail the difficulties I have they pale into insignificance compared to those experienced by others with more invasive or advanced forms of MND.

My own experience of health care and social services has been pretty good. There is certainly evidence of coordinated thinking. For example, even though I have no immediate need for intervention, my respiratory system is already being benchmarked and next week, a dietician and speech therapist are coming to visit. And tomorrow people are coming to fit me up with equipment that I can use with my feet so that I can answer the telephone and, most importantly, make sure that Sky Sports is permanently on the television.

However, there is continuing evidence that there is often a basic lack of understanding among health service and care professionals of how MND affects people.

For me, this became clear during a 36 hour stay in hospital for a heart procedure. I had to explain no less than 15 times to different people that I had MND and was not able to lift my arms for the blood pressure monitor, for injections or to eat. For me this was just an annoyance because I still have a voice. Imagine how you might be affected if you were unable to communicate.

While I understand where my journey with MND will eventually lead I prefer to remain positive and, to be honest, for me, that is easy, because inspiration is everywhere in this MND family. Who could fail to be inspired by two friends in their mid-50s cycling 1700 miles in your name to raise funds for the Association? Who could fail to be inspired by Liam Dwyer – a larger-than-life character now finding it difficult to speak, but who shouts louder than most as he campaigns ceaselessly for improved services for others? And who could fail to be inspired by Sarah Ezekiel – a lovely lady with hardly any use of her limbs or voice who simply comes to life through eye gaze technology and the ability it gives her to communicate and to create art.

I would like to welcome and to thank the many MPs for their attendance today.

For publicity value alone I would suggest that our cause is a very good one to get behind. Bolstered by the awareness created by the Ice Bucket Challenge, the film *The Theory of Everything* and a lot of

other activity we are planning, I can assure you that MND voices will increasingly be heard in the media, by people who can help make a difference, as well as by the “man in the street”.

But primarily, I would appeal to your humanity and compassion. There are an awful lot of issues to do with basic human dignity still to be addressed for those living with MND.

Writing about shortcomings in the provision of communications equipment in the Sunday Times recently, the 30-year-old Scottish Labour Party lobbyist, Gordon Aikman, himself living with MND said this.

“If you cut yourself, you get a bandage; if you break your leg, you get a plaster and pair of crutches. Yet if you lose your voice, there is no guarantee you will get the support you need. How utterly unfair and undignified.”

I recently became a Campaigns Contact for the MND Association and while I knew already of some of the issues I have been astonished to learn of a whole range of shortcomings in the supply of essential services for those living with MND.

I have learned of long delays for people with MND awaiting their disability allowances or PIP.

I have learned of staff at care agencies totally unprepared for the specialised needs of somebody in the late stages of MND.

I have learned of the “postcode lottery” nature of the provision of services. For example, while Sussex has two specialist MND nurses, neighbouring Surrey has none.

And I have learned of a lady trapped in her own home because her flat does not have the facilities to enable her to get out in her wheelchair, with little sign of help from the local council.

All of these examples run counter to the MND Charter, which we delivered to Downing Street today, and which many of you have signed.

The fact is that the clock ticks relentlessly for those living with MND. Another 3000 people will have passed away since NHS England became responsible for commissioning Communications equipment in October 2013. More than 80% of those will have experienced some loss of speech. While I am heartened to hear of improvements and to know that dialogue continues between the MND Association and NHS England on this issue, just one more person dying without the ability to communicate their dying wishes to their loved ones is one too many.

So thank you again for coming today. Your attendance is one thing but could I make a plea for you to go one step further? That is to find out more about and to support those among your constituents who live with MND, many of whom are here in the room. Through your actions you can help us ensure that the provisions of the MND Charter become a reality. Thank you.