

## **Sally Light's speech, parliamentary reception – 16 June, 2015**

Good afternoon and a very warm welcome to our reception.

It's lovely to see so many of our volunteers here today. I know many of you have travelled a long way and so we are particularly grateful for your support.

I would like to start by talking about motor neurone disease. It is hard to put into words the devastation that it causes. I have worked in health services for 35 years and MND is one of the most horrible diseases I have come across. It can strike any adult at any age and is always fatal. Unusually for diseases these days, there is only one treatment which has a modest benefit for some people and there is no cure. MND progressively robs people of the ability to walk, use their hands, talk, eat, and eventually breathe. Sadly, five people die from MND every day in the UK, 30% within 12 months of diagnosis, and more than half within two years.

Because of this, people need fast and reliable access to healthcare, social care, disability benefits and suitable housing. They need help to live their life to the full and die with dignity.

Unfortunately this doesn't always happen, which is why we launched the MND Charter in 2012. The Charter sets out what good care looks like for people with MND and their carers. Over the past three years we have been collecting signatures of support for the Charter and today we delivered those signatures to Downing Street.

I am delighted to announce that **33,630** people signed the Charter which is an incredible show of support for a relatively rare disease. People agree with us that, in a country like ours, those living with a devastating terminal condition should be able to access the support they need, when they need it.

I would like to thank everyone who has promoted the Charter in their local area over the last three years. This really is a tremendous achievement.

I also want to thank everyone who supported our general election campaign *Don't Let Me Die Without a Voice*, which focused on improving access to communication aids and equipment for people with MND. I particularly want to thank Charlie Fletcher for fronting the campaign and for being so fearless in sharing her story with the world. I am really pleased Charlie is here today with her now famous blue hair!

Charlie was joined in our campaign by our amazing Campaign Champions: Rita Beaumont, Greg Broadhurst, Jan Cousins, Liam Dwyer, Sarah Ezekiel, Helen Findlay, Tannwen Saunders, Heather Smith, Mark Stone, Mark and Katy Styles, and Helen Warren.

It was inspiring to see the lengths you went to to promote the campaign, including silent vigils, blogs, videos, and your Selfie Against Silence pictures which appeared all over social media.

We are so grateful to all of you for your hard work and dedication to improving the lives of those living with MND and for your recent support for our Voice Campaign.

We are in the process of gathering evidence on the current provision of communication equipment for people with MND and this will inform our campaigning work going forward.

Last summer we were amazed and thrilled by the publicity and funds that MND attracted from the Ice Bucket Challenge. An incredible £7 million was raised for the Association and, with the support of our members, we plan to invest the majority of this windfall in research.

You may know that June is MND Awareness Month and this year we wanted to take the opportunity to thank the general public for their generous support for the Ice Bucket Challenge. You may have seen our posters on the tube and national rail network on your way here today.

Thanks to two incredible people who are living with MND – Ailsa and Michael – we are again aiming to raise further awareness of MND. The MPs present may have seen the posters at Westminster tube station.

So what can you do as an MP to support people with MND?

Well,

- You can get to know your local branch or group, find out about services for people with MND in your constituency and take action to improve those services.
- You can join the All-Party Parliamentary Group on MND. It's holding its AGM in Parliament next month and we will be attending to talk about our current concerns about services for people with MND
- You can also meet us individually in Parliament. Our contact details are on the leaflet we have here today so please get in touch and we'd be delighted to meet you.

People with MND and their families may also need your support to access the services they desperately need. Please support your constituents and help where ever you can.

I would now like to introduce David Setters. David is living with MND and has agreed to talk today about the impact of the disease on him and his family.

David...

Thank you, David for speaking so honestly and openly about your experiences.

It now gives me great pleasure to introduce one of our Patrons, Charlotte Hawkins, who has a very personal reason for wanting to support the Association.

Charlotte...

Thank you Charlotte. That concludes our speeches and so it just remains for me to thank you all once again for coming and I hope you enjoy the rest of the event. Thank you.