

I wanted a diagnosis but not this



Heather and Tony Twine

HEATHER Twine received her diagnosis of MND in 2014. Now she has taken early retirement and has become an Association Campaigns Contact to help improve the care for people with MND.

"After three years of symptoms, I was absolutely desperate for a diagnosis. I wanted a label, a name, an explanation, and of course most of all I wanted to hear that there was a cure. I had heard of MND and the slower progressing form, PLS as they had been mentioned at consultations as possibilities.

"However I was actually desperately seeking another diagnosis. So hearing that it was confirmed as PLS, brought a short-lived elation, 'at last, something definite', followed swiftly by the deep dark pit, 'incurable, untreatable, progressive, neurodegeneration – deep joy'. I was alone in The National Hospital, London, so having the Association funded MND Care Co-ordinator, the wonderful Jan Clarke present and able to spend time with me, comfort me and hand me vital Association information was a great blessing. I can recall clutching those leaflets like a small lifeline.

"Six years ago I was a fully fit woman, holding down a high level charity director

post, managing a budget of over £20M, and staff group of over 1,000, with an active social life, including aerobics, skiing, tennis, dancing. Now, I've taken early retirement, as has my husband, Tony, to become my carer. I use a wheeled walker around the house, and have recently lost confidence to manage outside with two sticks, after several falls. So outside I use a mobility scooter or wheelchair.

"As a Campaigns Contact my message to Government is that this incurable, untreatable, deadly disease devastates lives, destroys families and deserves greater investigation."

"My voice is slowing and weakening and I've voice banked. The inevitability of it all can be quite saddening, and I do have some very down patches. I'm tired all the time and it's hard to get motivated to do anything much. But inside I'm still the old me. I still think of quick responses in conversations, but can't get the words out soon enough. I was always a great optimist and mostly I can get back to that glass half full perspective.

"I greatly value the work of the MND Association. Tony and I attended the Parliamentary Reception in October 2016.

It felt a bit like being back at work, in a good way. In past roles, I'd have been making the speeches, but it was familiar territory. And so afterwards, it felt natural to ask my MP why he hadn't turned up, and request a meeting to lobby for the Association. The role of Campaigns Contact was suggested to me, when I let the Association know what I was doing. My first target was getting Somerset County Council to adopt the Charter. A meeting with my local County Councillor went well, and she agreed to help.

"I tend to get fired up about all the possibilities and changes that could be made. In my head I have a full battle campaign to approach all five Somerset District Councils and the local hospitals too, and to go to all the non-adopting South West Local Authorities; but then I take a reality check and realise my very real limitations. One step at a time.

"As a Campaigns Contact my message to Government is that this incurable, untreatable, deadly disease devastates lives, destroys families and deserves greater investigation. The Association does great work, but we need much more awareness generally of what this disease does to people, and much more funding for research, for therapies, for support to help those affected."