

This Month's Spotlight! Local Campaigning in the South



The MND Association is collaborating closely with the MS Society in the Southern region to support local people affected by Motor Neurone Disease (MND) and Multiple Sclerosis (MS) in highlighting the negative impact resulting from a gap in locally commissioned coordination of care in Swindon. The Swindon based MND Quality and Training Clinical Care Coordinator was a twelve-month pilot post funded by the MND Association between 2016 and 2017. The pilot evaluation provided compelling evidence for the centralised coordination of care for MND patients, and their carers. Despite this evidence no further investment into a post to coordinate care for people living with MND has been given by Swindon Clinical Commissioning Group (CCG).

The North Wiltshire Group, MND patients, carers and professionals appreciate the financial pressures being faced by local healthcare services and associated difficulties in commissioning a condition specific post, so are working with the MS Society to ask for the pilot post evaluation findings to inform the commissioning of a wider progressive neurological conditions co-ordinator post in Swindon.

North Wiltshire Group Campaigns Contact Heather Smith met with MP for Swindon South Justin Tomlinson on 27th September to discuss these concerns joined by Regional Care Development Advisor Neil Drinkwater, Campaigns Manager for the South Rae Martin-Smith, MS Society Regional External Relations Officer Leila Middlehurst-Evans and MS Nurse Kate Widdows.

Justin expressed thanks for the well composed and evidenced campaigns brief, which included Great Western Hospitals NHS Foundation Trust data showing a 100% reduction in emergency department visits for patients living with MND, and a 50% reduction in the number of unscheduled admissions to hospital, resulting in an

inpatient stay, over the twelve-month period the MND Quality and Training Clinical Care Coordinator was in post (2016-2017). Data also pointed to a steady rise in non-elective admissions for MS patients since 2013 as MS nurses are no longer been able to conduct home visits due to capacity.

With the support of Justin Tomlinson MP the care coordination campaign members have secured a meeting with Swindon CCG on Wednesday 13th November to further make the case for funding into a progressive neurological conditions co-ordinator post in Swindon. It is hoped the post will provide the opportunity for patients to explore and discuss advance care planning and allow them to be better supported and die in their preferred place of care. With increasingly stretched health and social care provision it is vital that care is well coordinated, and both MND and MD patients receive the individualised and specialist care they need.

... and in the North, Campaigns Contact Emma Yates

As part of our continuing effort to work in partnership with the Lancashire Health and Wellbeing Board following their adoption of MND Charter, Sue Muller Regional Care Development Adviser, Pauline Callagher Specialist MND Nurse Co-ordinator at the Lancashire and South Cumbria Motor Neurone Disease Care and Research Centre, a person living with MND who uses both services, and me, Emma Yates, attended a meeting at the end of September with Councillor Shaun Turner, (chair) and Director of Public Health Sakthi Karunanithi, a key member of the Lancashire Health and Wellbeing Board.

Discussions focused on health and social care with a view to how improvements can be assessed and managed in order for a streamline fast track process to be attained for people affected by MND. Other issues that care centre staff experience on a daily basis, are not having a specific contact or person appointed as direct contact. Staff felt that having a number of the same conversations with numerous individuals was lengthy and time consuming. Dr Sakthi Karunanithi and Cllr Shaun Turner both agreed, and further discussions have been planned to investigate and seek a solution.

I feel as though being introduced through an 'in at the deep end' approach representing Central and East Lancs Branch has offered me invaluable breadth of knowledge in concerns that relate to health and social care, adaptations, I could go on, having recently taken up this post as Campaigns Contact and, I hasten to add 'fell on this path accidentally'.

The experiences profess that a continued alliance from within the MND Association, people living with MND, the Lancashire and South Cumbria MND Care Centre, Campaigns Contacts and volunteers enables a multidisciplinary approach that has a specific focus on people living the MND to advance talks with policy and decision makers.

The ongoing issues relating to these matters addressed above, indicate that there are continuing problems with care and support not being adequately provided for because of postcode lotteries. This is a cause for concern!



Many thanks to everyone who took the [Twitter action](#) marking the three-month anniversary of the announcement of the Department for Work and Pensions (DWP) review into the Special Rules for Terminal Illness (SRTI). Over 100 tweets were posted. [We also posted an update on our website.](#)

SCRAP 6 MONTHS

The new Secretary of State for Work and Pensions, Thérèse Coffey MP, gave evidence to the Work and Pensions Committee last week. We'd briefed MPs on the Committee to ask for an update on the review into terminal illness provision. Rosie Duffield MP (Canterbury) asked the question (thanks to Katy Styles, Campaigns Contact, for her help in arranging this). You can watch the question [here](#). We were very disappointed by the response from the Secretary of State and will be looking for more concrete answers when we attend the DWP roundtable on the review on 29 October.

Meanwhile we are asking clinicians to sign up to a letter to Thérèse Coffey supporting reform to the SRTI and will be publishing this ahead of the roundtable.

The Queen's Speech took place on 14 October – you can read our response here on [Twitter](#).

Conservative Party Conference in Manchester *Sue Heal*

I was delighted and terrified in equal measure when asked if I would join Alison Railton, Public Affairs Manager, in Manchester. Political turmoil meant this became a question of, 'Will you, won't you, will you, won't you, will you join the Conservative Party Conference?', apologies to Lewis Carroll. We debated the merits of attending given the likelihood of fewer MPs, and on Friday agreed to go for Sunday and Monday. Alison sent me a comprehensive briefing and list of fringe events we hoped to cover.

Before the first event I spoke with a number of people, exchanging reasons for being at 'Is welfare reform working? Poverty and hunger in modern Britain'. Then responsibility of speaking on behalf of people living with MND really struck home. After the presentations my heart was pounding as I stuck my hand up to ask my first question. The line up had changed, and there wasn't an MP to hear me speak about the problems faced by people needing to use the Special Rules for Terminal Illness (SRTI) and to question their support to 'Scrap 6 Months'. I was grateful to Helen Barnard, Deputy Director of Policy and Partnerships, Joseph Rowntree Foundation for sharing it in her tweet.

Next I went to the event on housing. Esther McVey MP spoke of the need for more accessible housing for which I thanked her, before asking if the government would commit to continued central funding for disabled facilities grants beyond the 2020/21 spending round. She expressed her support, something Alison would follow up later.

At 8am on Monday, I attended the Institute for Government's consideration of 'What does spending uncertainty mean for the health and care service'. The panel included Dame Donna Kinnair, Royal College of Nursing – what a privilege to hear her speak! Cllr Ian Hudspeth spelt out the constraints placed on local government funding for adult social care. I think all the speakers said, 'We need the green paper on social care'. I quoted from the 2019 Improving MND Care Survey and asked what the Government planned to do once the Carers' Action Plan comes to an end in 2020. I really wanted to be on the platform explaining just what it really feels like to spend more than 100 hours per week caring, being made to feel guilty for asking for respite to attend hospital appointments and so much more.

Then on to 'Where next for social care?', I was not picked to ask a question, but appreciated the carer who spoke of the need for respite and asked about increased Carer's Allowance, points we hoped to raise.

Finally, 'Beyond Brexit: where next for welfare?' an opportunity to raise Scrap 6 months again and to ask about transition from Legacy Benefits to Universal Credit.

There was not the same opportunity to lobby MPs as we might have hoped from a conference in normal circumstances. However, it was interesting to join Alison in conversation with a researcher, to meet my local County Councillor, to talk with people from other charities and to have the opportunity to input into research on transport facilities for people with disabilities.

Alison, thank you for guiding me through and giving me confidence. It was a pleasure to watch you in action and to learn. Would I do it again, oh yes!



Labour Party Conference Update

Senior Policy Adviser, Daniel Vincent, and Head of Policy and Campaigns, Susie Rabin, went to the Labour Conference in Brighton. The greatest benefit came from attending the fringe events, where we were able to get an insight into the party's thinking on key policy issues and where we raised concerns about Scrap 6 Months, social care and Universal Credit. Our time at Conference coincided with a Labour Party announcement to introduce free personal care to people aged over 65. Our reaction was one of disappointment that the announcement doesn't cover working-age adults. We raised the Scrap 6 Months issue with the Think Tank Institute for Public Policy Research, who we are going to follow up with as they look to produce further work on welfare issues. Following conference, the Labour Party also announced that they intend to scrap Universal Credit. We responded to this with a [statement](#) on our website.

Campaigns Day in London

Thanks to everyone who came along NCVO on 19th October – 13 volunteers attended, and it was great to see new and more established Campaigns Contacts there. In the morning we updated on our current campaigns and heard more about the current staffing reviews in the Association. Our Communications Manager, Suzanne Ostler, ran a great session on working with the media after lunch, leading to quite a frenzy of selfies and photo taking. Suzanne hopes to record a vlog on how to engage with the media for those volunteers who weren't able to attend on Saturday – so watch this space for further details. The slides from the day are up on Yammer (please remember that the final slide from Greg's work in Manchester shouldn't be distributed more widely at this stage). We'll be doing a short write up of actions and next steps that we'll post up on Yammer too.

Those attending have been sent a link to the evaluation form, so please do complete that and let us know how you found the day, which will help us plan further events.

