

Message from JC (Julie Compton, Campaigns Manager (North))



It was really great to be invited to attend the Yorkshire Dales Branch first committee meeting of the year. As Campaigns Manager covering the whole of the north of England and based at home, it is difficult for me to get to meet everyone in such a vast region, but this was a great opportunity to say hello, to talk about current campaigns and how everyone can get involved in some way or other.

The Scrap6Months Campaign is our current campaign. We are campaigning to change the law so that all people with MND are able to access benefits under the Special Rules for Terminal Illness (SRTI). Thank you to everyone who, over the last 6 months, has taken one or many of our campaigning actions to raise awareness of this campaign.

The latest phase of Scrap6Months Campaign is to encourage as many people as possible to sign our petition to pressurise the Government to change the law so that everyone with a terminal illness can access the welfare benefits they need quickly and sensitively. You can download a paper copy to collect even more signatures too! We don't have a closing date at the moment so please pass this petition around and to help you with this you can use our new video. Please see 'Michael's story', <https://www.mndassociation.org/news-and-events/awareness-campaigns/last-summer/michaels-story/> which we hope you like and will share widely!

We are currently planning and preparing for our next campaign which is all to do with housing issues. If anyone has good or bad personal stories about housing issues/adaptations/process etc we would love to hear from you, so that we can use them in our campaign, our reports and in our resources.

Champion the Charter – don't forget that second tier councils can also be approached to adopt the MND Charter, so there are still opportunities to approach the District Councils in your branch area, ie Selby / Harrogate / Craven / Richmondshire / Hambleton / Ryedale / Scarborough. Particularly as we will be working with second tier councils as part of our housing campaign.

Please contact me for further information; Julie Compton, Campaigns Manager (North), Motor Neurone Disease Association, Tel: 01159204507, Mobile: 07811280893, julie.compton@mndassociation.org

If you would like to be kept informed about our latest campaigns and want to take more campaigns actions then please sign up to our [Campaign Network](#)

[Scrap6Months Campaign](#) or <https://www.mndassociation.org/get-involved/campaigning-influencing/scrap-six-months/>

[Sign the petition online](#) or <https://e-activist.com/page/33936/petition/1>

[Download paper copies of the petition](#) or <https://www.mndassociation.org/wp-content/uploads/Scrap-6-Months-paper-petition-PDF.pdf>

[Housing campaign](#) or <https://www.mndassociation.org/get-involved/campaigning-influencing/take-action/accessible-housing-tell-us-your-story/>

[Join the Campaign Network](#) or <https://www.mndassociation.org/get-involved/campaigning-influencing/take-action/accessible-housing-tell-us-your-story/>

[Champion the Charter](#) or <http://www.mndcharter.org/>

[Campaigning highlights video for 2018](#) or <https://www.youtube.com/watch?v=tLN-J1m6vZc>

Happy New Year and welcome to the first P&C Round-up of 2019. It returned in June last year and we feel it has been a useful tool to share what we are working on, plans for the future, as well as relevant developments in the wider charitable sector and Government initiatives. We want your feedback. Please email us with suggestions for how it could be improved, how you use it, who you share it with. All comments very welcome. Get in touch with Helen Riley at helen.riley@mndassociation.org

This month's spotlight! We are delighted to hear from our Campaigns Contacts in the East...

Campaigning the North Bedfordshire Way! Rita Beaumont

This year we participated in the PIP Summer of Action; I met with two of the three MP's with constituencies in our area and this was followed by starting on the Scrap6Months campaign.

My personal highlight was being invited to present at the East Regional Conference. I talked about how we went about our successful local campaign to secure funding for the re-establishment of our own Specialist Nurse.

8 years ago a Specialist MND Nurse Post was funded by Sue Ryder Care for a 2 year period with understanding that the funding would be taken over by North Bedfordshire Primary Care. The impact of the post was rapidly evident. The vital importance of co-ordinated care became paramount but as funding period came to an end a problem occurred - the future funding of the post became caught up in NHS restructuring and Bedfordshire Clinical Commissioning Group (BCCG) became responsible for funding the post.

Action taken locally

A Campaign spearheaded by the local RCDA & Campaign Manager was launched and we collected evidence of negative impact the loss of Specialist Nurse was having on the lives of those living with MND and their carers. This was presented to Bedfordshire District Council Scrutiny group and two local sufferers made moving presentations which had considerable impact on the committee. The outcome was the BCCG were called to account and required to act on their promise to fund the post. In parallel local councillors and MP's were lobbied and added support and the NICE Guidelines were published providing a framework for good practice. BCCG met again with representatives of the Association and the outcome of negotiations was a post embracing MND plus Rare Neurological Diseases was agreed to be joint funded for two years, then 100% funded by BCCG at the beginning of 2018 after a few anxious weeks when the funding again seemed at risk.

Lessons learnt

Be systematic and be polite, patient and persistent - don't take no for an answer!! Evidence to support your case is key. Show impact on service provision; include how unneeded hospital admissions have been prevented and costs to service reduced. Learn to be political and use knowledge of who are the movers and shakers! And most importantly, use the experience of those living with MND.

On 10th December 2018 the 70th Anniversary of the signing of the United Nations Universal Declaration of Human Rights Day was celebrated. Eleanor Roosevelt who was the chair of the drafting committee said:

"Where, after all, do universal human rights begin? In small places, close to home -- so close and so small that they cannot be seen on any maps of the world. Unless these rights have meaning there, they have little meaning anywhere. Without concerted citizen action to uphold them close to home, we shall look in vain for progress in the larger world."

For me that sums up why I campaign ~it is about fighting for the human rights of those living with MND close to where I live in whatever way is necessary.

Achieving CCG charter adoption in Norfolk, by Sue Heal

In July 2017, the Branch chair and I attended a public Q&A session organised by Healthwatch Norfolk focussing on

the local Sustainability and Transformation Plan (STP). I asked, 'Can you confirm services for people with neurological disorders such as MND are being included in the STP process? How do you intend to improve these services?'

After the meeting we spoke with the panel, including Melanie Craig CO of NHS Great Yarmouth & Waveney CCG, who sounded agreeable to supporting the MND Charter. She nominated Dr Mark Lim to present the charter to the STP Clinical Care Reference Group.

Working alongside the local RCDA, Lindsay Goward, we met with Dr Lim, Programme Director Clinical Commissioning, Great Yarmouth and Waveney CCG. We jointly authored a paper for the Planned & Unplanned Care Clinical Network Meeting outlining the background to the Charter, provision of support offered by the local Branch and referencing the Norfolk MND Care and Research Network. It identified priorities for the CCGs if they signed the Charter. We included personal stories illustrating when delays in diagnosis, provision of equipment or appropriate care packages has caused significant distress to people with MND and their families.

In June, we presented the paper to the Network meeting, chaired by Dr Linda Hunter. We were interrogated by GPs and other health professionals. One GP suggested we should ask to bring MND into line with local Cancer provision, meaning that a referral from a GP should result in a consultation with a neurologist within two weeks. We were well received and asked if we wished to present a second paper to CCGs.

A second paper was written and submitted to the Joint Strategic Commissioning Committee (JSCC). The five CCGs voted unanimously to support the Charter.

The agreed actions are; to support in raising awareness of MND amongst professionals – including promotion of the Red Flag Tool to aid diagnosis; to promote the Association's educational resources amongst Health and Social Care Professionals; to be mindful of the rapid decline associated with MND during discharge and provision of end of life services; to raise awareness of the Norfolk MND Care and Research Network and the importance of GPs working in partnership with it; to support coordination between relevant specialities. We had been advised not mention the two week window from referral to consultant, but it was raised by a Committee member before the final vote; everyone agreed that this should be their goal.

We hope to see tangible benefits as a result of the Charter's adoption, and to maintain the relationships forged throughout the campaign.



We'd like to thank you all for the campaigning you have done this year, helping to create change for people with MND. We're delighted to share our ['Campaigning Highlights of 2018'](#). None of these achievements would have been possible without the hard work and dedication of our campaigners and supporters and we look forward to campaigning with you in 2019!

We have launched a new petition as part of the Scrap6Months campaign. Over 2,000 people have signed it so far. If you haven't signed yet, please do [here](#) and encourage others to add their signature too. Supporters can download a [form](#) and use to collect signatures from their contacts which is available online and in Thumb Print, which members will receive shortly.

SCRAP6MONTHS
Northern Ireland

Following the successful campaign by MND Scotland and Marie Curie Scotland to change the legal definition of terminal illness as it applies to the SRTI fast track process when applying for benefits, we began work in Northern Ireland in April with Marie Curie NI to lobby the Department of Communities (which has responsibility for administering devolved benefits such as PIP) and Members of the Legislative Assembly (MLAs) to support the same change once the Assembly is sitting again.

Since this NI campaigning started, the MND Association launched the Scrap6Months campaign to call for legislative change across the UK, leading us to also work with MPs and Lords from Northern Ireland.

We published a joint briefing with Marie Curie NI on the 31st May and a letter calling for the change was published in the Belfast Telegraph in June signed by 60 clinicians from the province. Colm Davis, our Campaigns Contact in Northern Ireland, has been interviewed several times on the BBC and in press, and has met with many of the MLAs, MPs and Lords.

A key feature of our campaigning has been getting cross-party support. On the 18th June, all political parties (DUP, Sinn Féin, SDLP, UUP, Alliance and Green Party) signed a joint letter to the Permanent Secretary of the Department for Communities asking for a working group to be established to *"proactively engage with Scottish officials and other stakeholders to review the current definition and begin the preparatory work required, including an analysis of implications, for the introduction of a definition of terminal illness based on clinical need, rather than any time-restricted understanding of life expectancy"* in Northern Ireland.

The Department of Communities commissioned an independent review of PIP which led to a recommendation that *"the clinical judgment of a medical practitioner, indicating that the claimant has a terminal illness, should be sufficient to allow special rules to apply. The 6 months life expectancy criterion should be removed"*. However, the Department of Communities has concluded that the law does not allow it to make this change unless there is a similar change in UK legislation or there is a NI government to propose the change to the NI Assembly. Several local councils have passed motions calling on the Secretary of State for NI to implement the change to the definition in the absence of the Assembly. In October, Lord Rogan of the UUP spoke in favour of changing special rules in the House of Lords.

The issue has a high public profile in Northern Ireland. The latest coverage was on the 14th December when the Belfast Telegraph published a powerful [article](#) about Lorraine Cox, aged 39 and a single mother of three children. Lorraine is living with MND and was turned down for PIP. After going to appeal, she was awarded the lower rate. Because of the unpredictable nature of MND she has been unable to apply through SRTI which would have simplified and speeded up the application process, removed the need for face-to-face assessments and put Lorraine straight on to the higher rate for PIP.



Photo of Hartlepool Council MND Charter adoption

2018 was full of great adoption work. Here are just a few examples from the North and South regions...

Plymouth City Council: Kerry Palmer (RCDA for Cornwall, Devon & Somerset), and a local volunteer affected by MND will be presenting a one hour MND awareness and information training to Councillors. This has been organised through the council's Dementia Friendly City Co-ordinator.

Surrey County Council: RCDA Jane Giles met with the Surrey Equipment and Adaptations Project Manager to discuss changes to housing adaptation work following a recent county-wide review. The Council have expressed a desire to collaborate on area based workshops with occupational therapist (OTs), Home Improvement agencies, and District/Borough council grant officers. Workshops will explore best practice and timely interventions for equipment and adaptations for people living with MND. Jane has been invited to deliver an MND Awareness session to the Council's newly qualified OT forum.

Bradford, Doncaster and Hartlepool Councils all adopted the charter this year and in Hartlepool a social worker was designated specifically for people living with MND. The Charter was also adopted by **Rotherham, Doncaster and South Humberside NHS Foundation Trust**. Lancashire County Council has been a really slow burn in 2018 despite the enthusiasm of our Campaigns Contact and the Lancashire and South Cumbria MND Care Centre. We will follow this up in 2019.

Tewkesbury Borough Council: A MND awareness session was delivered by the RCDA Neil Drinkwater, and the Campaigns Contact for the Gloucestershire Branch Alan Marsh, to the Head of Community Services, the Head of the Health and Wellbeing Board, council partners, and colleagues.

Basingstoke and Deane council: the council will be working closely with JobCentre Plus on applications for disability payments, and ensure those living with MND are able to make vital adaptations to their homes through Disabled Facilities Grants.