

This month's spotlight! Policy with Alex Massey and Daniel Vincent



We're delighted to have the chance in this month's update to talk about our work in more detail. For those of you who haven't come across us yet, we're Alex and Daniel, and have been working for over two years as the policy arm of the wider campaigns team. Whilst there isn't enough space in this update to detail everything we do, broadly speaking we're here to identify, analyse and influence the policies that will have an impact (good and bad) on people living with and affected by MND. What this looks like in practice varies a lot depending on what we're working on. It includes, but isn't limited, to conducting our own research, producing policy documents such as briefings with recommendations, responding to consultations and representing the Association at key meetings with influential bodies such as the NHS and Government departments.

The work we do is often 'behind the scenes' in nature, but policy work also contributes to the more high-profile campaigns we're all involved with. As a team we work very closely with our other colleagues in public affairs and campaigning to also give policy input into the issues they work on, including on the issues they will work alongside you with locally.

In terms of focus we typically work across Health, Social Care, Carers, Welfare, Housing and Research policy. Each of these overarching areas contain numerous policy issues that we work on. As a relatively small team, being able to prioritise and be strategic about the policy issues we focus on is important.

So, what are we currently working on? It probably won't come as a surprise that welfare benefits continue to be a big focus for us. We're working in this area on several fronts, including policy work for the Scrap 6 Months campaign and also engaging with the Department for Work and Pensions (DWP) to input into their plans for the move of disabled people from the old benefits system onto Universal Credit (due to start in the form of a pilot from July this year).

We're also working on a range of issues across health and social care, from investigating the current supply of [Riluzole](#) to working with NHS Rightcare to develop a pathway for progressive neurological conditions. We also continue to play an active role as part of the [Neurological Alliance](#) and the [Care and Support Alliance](#) on health and social care issues.

Our work in support of the upcoming housing campaign continues with a policy report on the way, and Alex came along to the Campaigns Day in March to talk about our work in that area.

Whilst what we've included here only scratches the surface of what we're up to as a team and is by no means exhaustive, we hope it gives you an insight into what we do and some of the issues we work on. We'll continue to keep you updated via the Round-up and other channels too. As ever, if you have any queries about our policy work in the meantime then don't hesitate to get in touch. Or feel free to raise anything through your campaigns manager or coordinator as well.

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SCRAP 6 MONTHS

The Association recently engaged with the Department for Work and Pensions (DWP) to bring about vital changes to their guidance for medical professionals when deciding if their patients should access the Special Rules for Terminal Illness (SRTI) fast-track for welfare benefits.

Importantly, the updated guidance now makes it clear that the benefits fast-track is not only for people living with terminal cancer. It now also recognises that providing a prognosis is not an exact science and needs to be based on the 'balance of probability.' In addition, the new guidance makes clear that clinicians can initiate conversations with their patients about accessing financial support for the terminally ill, without waiting to be asked.

However, the Association is clear that although this is an important step forward, there is still more progress to be made. There is still a legal requirement for "a reasonable expectation of death within six months" in order to access the terminal illness fast-track, which is not appropriate for complex and unpredictable terminal conditions such as MND. Consequently, we believe the changes to the existing guidance do not go far enough.

We will therefore continue our [Scrap 6 Months](#) campaign, in partnership with Marie Curie and others, to change the law to scrap the six-month time limit in order to create a compassionate and effective benefits system for people living with a terminal illness.

In April we attended a meeting with Amber Rudd MP, Secretary of State for Work and Pensions, alongside Madeleine Moon MP and Marie Curie. We're also due to meet Justin Tomlinson MP, the newly appointed Minister for Disabled People, Health and Work, next month. These meetings are designed to keep the pressure on the Government to reform SRTI.

Carers Week 10 - 16 June

This year we are again joining with other charities to promote the needs of carers during Carers Week in June.



We attended the [Carers Week](#) round table with Caroline Dinenege MP, Care Minister, in March and we'll be attending the parliamentary networking event in June alongside carers of people with MND.

At the recent housing adaptations campaign planning day, we agreed to develop an online form to make it easier for you to help gather personal stories to support our upcoming campaigning work. Please see here the [online form](#)



We have a few leads for personal stories from regional staff and volunteers - thank you to those who have shared these with us. However, we are keen to hear if there are any more that could be useful for our campaign.