



Impact of the Social Services and Well-Being (Wales) Act 2014 in relation to carers in Wales

The MND Association welcomes the opportunity to respond to Welsh Government's request for written evidence into the inquiry on the impact of the Social Services and Well-Being (Wales) Act 2014 in relation to carers. People affected by MND have fed directly into the inquiry via a focus group – here we enclose some additional information from the results of our *Improving MND Care Survey 2017* as well as some general points about MND itself and the impact on carers, their care and support.

MND is a rapidly progressing disease of the brain and nervous system. MND kills a third of people within a year and more than half within two years of diagnosis – there is no cure. As the condition rapidly progresses, the severity of the needs associated with MND means that caring for a person living with the condition can be extremely intense, exhausting and demanding. Well over half of carers of those with MND devote more time to their caring responsibilities than they would in the average full-time job. Therefore, speedy assessments and support for carers of those with MND is all the more important in this context.

Carer's Assessments

In our recent *Improving MND Care survey* we found, that, only 30% of our respondents who are carers in Wales have had an assessment of their needs or are in the process of having one (this matches similar statistics to our respondents in England where the legislation has been in place for longer)¹. Many carers do not know about their rights under the SSWB Act and our survey suggests that more needs to be done to promote this right.

Additionally, recent research by Carers UK found that 39% of people caring for someone at the end of life waited 6 months or more for their assessment². Timely access to an assessment is critical for carers of those with a rapidly progressing condition like MND.

Policy recommendation: The right to an assessment of support for carers is promoted more widely, particularly at the point of diagnosis. Carers of people with progressive and terminal illnesses like MND must be fast-tracked for assessments.

Respite care and provision of support

¹ MND Association (2018) *Improving MND Care Survey*

² Carers UK (2016) *State of Caring 2016*

Over half of carers (52% of our respondents in Wales) spend 50 hours plus caring for people with MND³. Provision of support such as respite or short breaks can be a lifeline for maintaining the health and well-being of the person providing care.

Only two fifths of our respondents had taken any planned breaks even for as short as two hours and many have to rely on family and friends to enable them to do so⁴.

Respite care is oftentimes not offered, not available or prohibitive to carers because of their finances:

[I need] financial support for helping to pay for carers for respite or a regular help to take the emotional and financial pressure off the families.

MND Association Carers Survey 2015 respondents⁵

Sometimes people are unwilling to take respite for concerns about the quality and expertise of care agencies and providers. MND is a particularly complex disease and any provision of respite care must be delivered by high quality services with the right expertise. Additionally, we need to see the development of availability of respite at hospices where, at present, it is very limited.

We welcomed the Welsh Government's 3 million investment into respite care to local authorities as part of the Ministerial Advisory Group for Carers, Annual Plan 2018-2019. We await the interim reporting on this and the impact it could potentially have on respite care for carers of those with progressive conditions like MND, and in areas of provision where there are limited respite facilities; e.g. hospices. We further recommend that an assessment of how the funding was spent identifies the support for those caring for people with complex diseases like MND in order to identify gaps, and plan for future provision in Wales.

Policy recommendation: Welsh Government should seek an evaluation of the impact of the 3 million funding on respite provision in Wales. This evaluation should specifically identify quality and quantity of respite provision and support for carers of those with complex conditions.

To consider broader Welsh Government policy on carers

The Ministerial Advisory Group on Carers has a dedicated action plan for 2018/19 - including dedicated funds for respite provision (as mentioned above), awareness raising in primary care as well as funds for third sector provision. **We suggest that an evaluation and detailed analysis and progress towards this action plan and funding will help to identify gaps in current support and plan for support for carers post 2019.**

Additionally, whilst we recognise that benefits for carers are not within the scope of the inquiry, Carer's Allowance simply does not provide enough financial support for carers. In Scotland, Carer's Allowance is going up by £8.50 per week to the same level as Jobseeker's Allowance and we support the current campaign by Carers UK to raise the amount in other parts of the UK to the same amount.

Policy recommendation: We would like to see Carer's Allowance increased to at least the value of Jobseekers Allowance and introduce a taper that facilitates carers who

³ MND Association (2018) Improving MND Care Survey

⁴ Ibid

⁵ MND Association (July 2015) Experiences and views of carers of people living with MND

need to transition out of work as their caring role increases and move back into work gradually after bereavement.

About MND and the Association

- i. Few conditions are as devastating as motor neurone disease (MND). It is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves that control movement so that muscles no longer work. There is no cure for MND.
- ii. While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, talk, swallow, and ultimately breathe. Speech is usually affected, and many people will lose the ability to speak entirely. Some people with MND may also experience changes in thinking and behaviour, and 10-15% will experience a rare form of dementia.
- iii. MND kills a third of people within a year and more than half within two years of diagnosis, typically as a result of respiratory failure. A small proportion of people experience slower progression and live with MND for longer, but survival for more than ten years is highly unusual.
- iv. A person's lifetime risk of developing MND is up to 1 in 300. It can affect any adult, but is more common in older people: it is most commonly diagnosed between the ages of 50 and 65. There are about 5,000 people living with MND in the UK, approximately 250 of them in Wales.
- v. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer-led branches and 3,000 volunteers. The MND Association's vision is of a world free from MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.

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