



motor neurone disease
association
cymdeithas
clefyd motor niwron

National Assembly for Wales / Cynulliad Cenedlaethol Cymru
[Health and Social Care Committee / Y Pwyllgor Iechyd a Gofal Cymdeithasol](#)

[The Care and Support \(Eligibility\) \(Wales\) Regulations 2015 / Rheoliadau Gofal a Chymorth \(Cymhwysra\) \(Cymru\) 2015](#)

Evidence from Motor Neurone Disease Association - CSR 06 / Tystiolaeth gan Cymdeithas Clefyd Motor Niwron- CSR 06

Response to the Care and Support (Eligibility) (Wales) Regulations 2015 Scrutiny Period

1. Introduction

- 1.1 Few conditions are as devastating as motor neurone disease (MND). It is rapidly progressive in the majority of cases, and is always fatal. People with MND will, in varying sequences and combinations, lose the ability to speak, swallow and use their limbs; the most common cause of death is respiratory failure. Most commonly the individual will remain mentally alert as they become trapped within a failing body, although some experience dementia or cognitive change. There are about 5,000 people living with MND in the UK. A third of people with the disease die within a year of diagnosis, and more than half within two years. There is no cure. There are about 5,000 people living with MND in the UK, approximately 250 of them in Wales. Half of people with the disease die within 14 months of diagnosis. There is no cure.
- 1.2 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.
- 1.3 People living with MND will have a range of care needs and be in contact with a wide range of services. People who provide care for people living with MND will also have considerable support needs to help them manage their caring responsibilities. For people with MND it is therefore crucial that services take a joined-up approach to care and consider the full range of needs so that people are able to maximise their own wellbeing. This response focuses on the likely

consequences of the draft regulations and Code of Practice for people with MND and their carers.

2. The likely consequences of the draft Regulations for people with MND and their carers.

- 2.1 The MND Association welcomes the standardisation of eligibility regulations under the Social Services and Wellbeing (Wales) Act 2014. It also welcomes the approach to determining eligibility based on ability to achieve well-being outcomes. The list of needs that fall under the eligibility criteria is comprehensive and includes communication needs, which is an important issue for many people with MND.
- 2.2 The Association welcomes the distinct eligibility criteria for carers focussed on the carer's ability to achieve personal outcomes, and particularly the consideration of whether they are prevented from fulfilling those outcomes as a result of the level of care they are providing without local authority support for either the carer or the person receiving care (section 5 (d)).
- 2.3 However, we are concerned about the principle underpinning the National Eligibility Framework, that individuals will only be eligible for local authority support if services in the community are either not available or not adequate, or if a carer is not willing or able to provide that care and support (section 3 (c)). We strongly recommend that this principle is re-worked comprehensively, to remove the substantial barriers that it seems to erect to timely access to appropriate care. Eligibility should be based on what a person needs in order to achieve their personal wellbeing outcomes, rather than what support is available from which sources. We believe that eligibility for support should be determined based on this principle, and the care planning process should determine who has the right skills and capacity to fulfil each need.
- 2.4 The Association believes that this bar of eligibility will leave people at risk of receiving low quality or inadequate support for a significant period before the local authority is able or willing to step in. People with MND will often have specialist and complex needs, requiring a particular level of expertise that may not be available in community services. However, they may have to show that they have exhausted the capacity of local, more generalist services, to meet their needs before they can access the appropriate services. This creates a serious risk that people with a rapidly progressive condition could face unnecessary delays in accessing services. While the legislation and Code of Practice on this subject create discretionary powers to meet needs locally, we anticipate that these will be exercised inconsistently between local authorities, and will not consistently overcome this problem of delayed access to services for people with MND.

- 2.5 While we appreciate the importance and value of services provided by voluntary organisations articulated in the Code of Practice, and agree that some people with MND can benefit significantly from existing community providers, ultimately these services lack close oversight and inevitably offer a variable quality of care. We are therefore not convinced by an approach that requires people with MND to make heavy use of these services before accessing more specialist social care.
- 2.6 Finally, the Association believes that the eligibility criteria may place undue pressure on families and others to provide care. While we welcome the recognition in the Regulations that the local authority will need to provide care to someone whose carer's own wellbeing would be compromised by their caring role, we believe that this places a substantial burden of proof on the person who needs the care. Anyone who cannot meet this burden of proof will be denied services, which concerns us greatly. An assessment of needs and a carer's capacity must be comprehensive in order to determine the real level of support a carer is able to provide, and the system must have the capacity to react swiftly to changes in the carer's circumstances and the level of care required by the person with care needs.

3. Conclusion

- 3.1 The MND Association welcomes the opportunity to feed into this scrutiny period. We broadly welcome the move to establish a single national eligibility threshold, and agree with the adoption of a person-centred approach and a focus on well-being outcomes.
- 3.2 However, the Association hopes that the Health and Social Care Committee addresses the concerns expressed above about the principle of eligibility based on an absence or failings of alternative services. We believe that this risks delays in or exclusion from appropriate services for people with MND and undue pressure on their carers.

For further information contact:

Ellie Munro
Policy Officer
MND Association
David Niven House
10-15 Notre Dame Mews
Northampton
NN1 2BG



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