

**mnda**

motor neurone disease  
association  
cymdeithas  
clefyd motor niwron

National Assembly for Wales election 2016



# MND Won't Wait

Championing care for people with motor neurone disease

## Summary

**We are asking Welsh Assembly candidates and the Welsh Government to ensure people with motor neurone disease (MND) have the support they need to maintain as high a quality of life as possible and to die with dignity.**

Our three key requests are:

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**Continued and enhanced support for the prompt and accurate diagnosis of MND – in particular the promotion of our bilingual Red Flag tool which helps GPs to identify possible signs of MND and refer to neurology.**

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**Implementation of new best practice in care and support for people with MND – such as the new National Institute for Health and Care Excellence (NICE) guideline.**

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**For Assembly members to champion the needs of people with MND in their constituency or region, including encouraging local councils to adopt the MND Charter.**

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We also make recommendations to ensure the new care framework set out in the Social Services and Well-being (Wales) Act 2014 provides improved outcomes for people with MND and their carers.

## About motor neurone disease

**Motor neurone disease (MND) is a fatal, rapidly progressing disease of the brain and central nervous system. It attacks the nerves that control movement so muscles no longer work. There is no cure for MND.**

While symptoms vary, over the course of their illness most people with MND will become unable to walk, to use their hands, to swallow, and ultimately to breathe. They will find that their speech is affected, and many will lose the ability to speak entirely. Some people with MND may also experience changes in thinking and behaviour, with a proportion experiencing a rare form of dementia.

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 have a more slowly progressing version and survive for longer, but more than ten years is highly unusual.

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: approximately two thirds of people are diagnosed between the ages of 55 and 75. At any time, around 210 people are living with MND across Wales and around 60 people will be diagnosed each year. However, numbers do fluctuate, and we believe the current total to be somewhat higher.

To help coordinate essential support, the MND Association funds a Care Network for South Wales and a Care Centre at the Walton Centre NHS Foundation Trust for North Wales. We support multi-disciplinary coordinated care in Mid Wales.

## Right diagnosis, right time

**The rapidly progressing and serious nature of MND means that a timely and accurate diagnosis is essential in order for the right care at the right time to occur.**

Wales has made some progress on this issue; the *Neurological Conditions Delivery Plan*<sup>1</sup> of 2014 made diagnosis one of its key priorities. In 2014, the Government also asked the Health Boards to distribute our *Red Flag*<sup>2</sup> tool. Created with the Royal College of General Practitioners, this tool helps GPs identify possible signs of MND and refer to neurology.

However, having surveyed the views of people with MND in 2013 and then in 2015 audited standards of care across Wales, there remains much to be done to ensure prompt diagnosis.

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**In 2013, one in five people with MND surveyed in Wales waited longer than a year after first having visited their GP to see a neurologist for diagnosis.**<sup>3</sup>

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*“My husband had been visiting his GP for over two years with symptoms like weight loss, changes to his gait, indigestion and problems with his hands. During this time he’d had a lot of tests and hospital visits but no answers. He’d never been referred to a neurologist until finally we took him into hospital and asked for a definite diagnosis.”*

*“The GP had no experience of motor neurone disease, but I had found out by putting my husband’s symptoms into the laptop.”*

*– partner of a person with MND*

Despite the creation of fast-track processes for people with rapid progression, once a referral is made delays still occur. The Welsh Government’s *Neurological Conditions Delivery Plan Annual Report* from 2015 suggests that more than one in ten people with a neurological condition in Wales wait more than six months for their first neurology outpatient appointment.<sup>4</sup>

## Recommendations

**We are asking the Welsh Government (and where appropriate Assembly members) to champion the prompt and accurate diagnosis of MND, including:**

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**Supporting and evaluating the ongoing dissemination of the Red Flag tool to GPs and other health professionals by the Health Boards.**

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**Promoting the new Welsh-language version of the Red Flag tool.**

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**Requesting future neurological reporting includes data on diagnosis, so performance in this area can be monitored.**

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**Working with and incentivising care professionals and Health Boards to improve existing processes of referral and diagnosis.**

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1 Welsh Government, Together For Health – A Neurological Conditions Delivery Plan, 2014.

2 MND Association, Red Flag diagnosis tool, 2013.

3 MND Association, Improving MND Care, 2013. The Association is currently conducting another survey of people with MND and will publish the results later this year.

4 Welsh Government, Together for Health Neurological Conditions Delivery Plan, Annual Report, 2015.

## Bringing in new best practice

**Motor neurone disease poses one of the sternest challenges to any system of care and support. The disabling effects of MND mean care rapidly becomes complex, requiring the involvement of many disciplines. A person with MND can have over a dozen professionals involved in their care at a time. Clear guidance is therefore essential – many GPs will encounter only a handful of cases in their entire career.**

**The National Institute for Health and Care Excellence (NICE) guideline on MND represents the most authoritative and up to date statement of best practice, and should be vigorously implemented by the Welsh Government and Health Boards.**

The MND Association has also developed an outcomes-based tool for assessing the quality of MND care. We would be happy to work with the Welsh Government and Health Boards to employ our Outcomes Standards to monitor the effectiveness of MND care in Wales.

## Supporting the best approach to care

**Generally the best approach is to keep the person as well as possible in their own home. This means care will often be split between a hospital (on an outpatient basis) and community services, both NHS and social care. Care must also be anticipatory: for a rapidly progressive condition such as MND, poor forward planning can leave care services reacting too late to a crisis that could have been prevented.**

Given the number of professionals involved it is vital that care is well coordinated, preferably by a named individual with expertise in MND. This could be an MND care co-ordinator, or a specialist nurse or other

therapist playing a similar role – in a hospital clinic or community setting. Care must be planned in collaboration with the person with MND.

## The impact of multi-disciplinary teams – Roger's story



*"I am extremely fortunate in that I have survived MND for over ten years. During that time I have seen a vast improvement in the care provided through the creation of multi-disciplinary teams (MDTs), particularly the one I use which is based at the Hafan Menai Hospice at Ysbyty Gwynedd."*

*"About five years ago I was having problems with my feeding tube. I told all the medical staff I could*

*think of. When I was eventually admitted for an emergency procedure the first thing the consultant said was, 'This should have been brought to my attention far earlier!'"*

*"This would not happen now the MDTs have been created. My health is now monitored on an ongoing basis and the MDT meets to discuss my case regularly. If I develop a problem and I'm not sure who to contact, I just ring the hospice and they arrange an appointment with the appropriate person. This not only means that any discomfort is treated as rapidly as possible but also gives me great peace of mind."*

*– Roger Sowersby, North Wales.*

## The view from North Wales

**North Wales has been working towards providing exemplary proactive care for people living with MND through a model of multi-disciplinary team working linking with the Walton Centre in Liverpool.**

In 2012 Betsi Cadwaladr University Health Board established the North Wales Neurosciences Network to advise on the strategic clinical direction and operational delivery of neurological services. With input from the MND Association, the Network set up a Disease Specific Advisory Group (DSAG) for MND as a successful vehicle for service planning and development.

Historically, there has been some evidence from people affected by MND and care professionals of poor coordination and communication as well as of diagnostic delay. To help address these issues, in 2015 the DSAG proposed an MND Care Co-ordinator role for North Wales. This role is now being implemented by the Health Board with developmental funding from the MND Association.

## The view from South Wales

**Since it was established with the ongoing financial support of the Association, the South Wales MND Care Network has transformed care for people affected by MND. It provides co-ordinated services locally through multi-disciplinary teams (MDTs) and clinics across the whole of South Wales. It also raises awareness and understanding of MND, for example through study days for health and social care professionals.**

*"It's really good to be able to see everyone at the same clinic, and the care is much more co-ordinated."*  
– person with MND

*"I feel much more supported in caring for people with MND, I no longer have to deal with this on my own and referrals are much easier."*  
– consultant neurologist

However, challenges remain, particularly the inconsistent provision of services across the Health Boards. This 'postcode lottery' affects the level of support people with MND will receive, including access to respiratory services, psychological services, appropriate respite care, approaches to gastrostomy (feeding tubes) and the provision of vital equipment.

## The view from Powys

**Powys has no district general hospitals and commissions neurology services from neighbouring health boards and trusts in England and Wales. The low population density and long travel times present challenges to ensuring access to specialist services for people affected by MND as well as in coordinating their care.**

With the support of the Association, Powys Teaching Health Board has set up virtual multidisciplinary team meetings across the county using tele- and

videoconferencing. Evaluation of the meetings so far suggests they are helping to coordinate and improve care provision.

## A new care framework

**Due to come into force in April 2016, the Social Services and Well-being (Wales) Act 2014 will provide a new care framework for people with MND and their carers.**

Like other charities, we raised concerns about the potential effects of the 'can and can only' eligibility principle in the Act. Under this principle people will only be eligible for local authority support if there is no alternative available from either the community or a carer.

In response to these concerns, the Government gave assurances to the Assembly that assessments would still find people to be eligible for care, without placing onerous requirements on them to have exhausted all other possible options. It also committed to evaluate the impact of the changes.

We welcome these assurances, but are concerned that some risk remains: could eligibility for social care be made unacceptably tight, particularly if a shortage of funding creates pressures to reduce service demand?

We are therefore calling on the Welsh Government for a commitment to amend the regulations, if it

becomes clear during the next Assembly term that people with MND and other social care users have been disadvantaged by them.

In addition, in order to realise the wider benefits of the Act, the following commitments must be in place:

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**There must be sufficient, protected funding at a national and local level for the delivery of social care services so everyone gets the support they need, as soon as they need it.**

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**People with MND must be able to make a real choice about where they receive their care, whether in their own home or in a residential setting that provides for their full range of needs.**

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**Health and social care professionals must work together to ensure care is coordinated across teams, is consistent and continuous as circumstances change, and takes account of future as well as current needs of people with MND.**

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## Supporting carers

**There are more than 370,000 unpaid carers in Wales, providing care estimated to be worth £8.1 billion a year. 28% of these carers provide over 50 hours of unpaid care per week.<sup>5</sup> More than half of family members and friends who care for people with MND provide over 100 hours of care per week.<sup>6</sup>**

This growing group of people need specific support in order to ensure their health and wellbeing; it is welcome, therefore, that the Social Services and Well-being (Wales) Act explicitly includes carers in its scope. However, these new provisions will require funding if they are to be fulfilled.

We are therefore asking candidates to support the following principles, based on positions taken by the Wales Carers Alliance, Carers Trust Wales and Carers Wales:

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**Ensuring that sufficient funding is in place to implement the new duties introduced by the Social Services and Well-being (Wales) Act.**

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**Ensuring that all carers are better able to access breaks, to relieve stress and strain on carers through a dedicated Carers Wellbeing Fund.**

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**Improving the commissioning, funding and development of preventative services for carers in order to prevent them reaching crisis point.**

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<sup>5</sup> Carers Wales, Carers Manifesto, 2015.

<sup>6</sup> MND Association, Experiences and views of carers of people living with MND, 2015.

## Championing local care – the MND Charter

**We are urging all councils across Wales to adopt the MND Charter. Assembly members and candidates can support local campaigns to make this a reality.**

Many decisions about services used by people with MND, such as social care, housing adaptations and support for carers, are made at the local level by councils. As such, it is important that councillors, and all those working to provide services for the council, understand the needs of people with MND.

By adopting the Charter, the council can help positively influence the quality of life for local people with MND and their carers. The Association will provide councils with ways they can help raise awareness and achieve better outcomes for those living with the disease.



The five points of the MND Charter are:

- 1. People with MND have the right to an early diagnosis and information.**
- 2. People with MND have the right to access quality care and treatments.**
- 3. People with MND have the right to be treated as individuals and with dignity and respect.**
- 4. People with MND have the right to maximise their quality of life.**
- 5. Carers of people with MND have the right to be valued, respected, listened to and well-supported.**

## About the MND Association

**The MND Association was founded in 1979 by a group of volunteers with experience of living with or caring for someone with MND.**

Since then, we have grown significantly, with an ever-increasing community of volunteers, supporters and staff, all sharing the same goal – to support people with MND and everyone who cares for them,

both now and in the future. We are the only national charity in England, Wales and Northern Ireland focused on MND care, research and campaigning.

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