

Lancashire Health and Wellbeing Board

Meeting to be held on 29 January 2019

Adoption of the Motor Neurone Disease Charter by Lancashire County Council

Contact for further information:

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Executive Summary

Motor Neurone Disease (MND) is life shortening and there is no cure. Motor Neurone Disease can affect how you walk, talk, eat, drink and breathe.

Although the disease will progress, symptoms can be managed to help achieve the best possible quality of life.

The Motor Neurone Disease Charter (Appendix 'A') was created to raise awareness and campaign to improve services for people with MND and their carers at a local level and is a statement of the respect, care and support that people living with Motor Neurone Disease and their carers deserve and should expect.

Whilst this campaign has been aimed at Councils, due to the efforts of our campaigners and people living with/affected by Motor Neurone Disease, there have also been a number of adoptions by NHS Trusts, Clinical Commissioning Groups, Health and Wellbeing Board partners etc.

Adoption of the MND Charter will mean that:

- Lancashire County Council demonstrates a commitment to the local Motor Neurone Disease community;
- Councillors gain an increased awareness of the devastating impact of Motor Neurone Disease;
- Lancashire County Council will work in partnership with the Motor Neurone Disease Association and the Lancashire and South Cumbria Motor Neurone Disease Care and Research Centre to support people living with Motor Neurone Disease;
- The Motor Neurone Disease Association will offer Charter resources and training opportunities to further raise awareness of Motor Neurone Disease.

Recommendations

The Health and Wellbeing Board is recommended to:

- i) Adopt the Motor Neurone Disease Charter.
- ii) Designate a Motor Neurone Disease Champion to work in partnership with the Motor Neurone Disease Association.
- iii) Use Motor Neurone Disease resources to raise awareness of Motor Neurone Disease with councillors, staff and partners
- iv) Encourage Health and Wellbeing Board partners to adopt the Motor Neurone Disease Charter.

Background

Motor Neurone Disease affects up to 5,000 adults in the UK at any one time and in Lancashire there are approximately 110 people living with Motor Neurone Disease.

As this is not a common disease, general health and social care professionals may not see many cases of Motor Neurone Disease. This means it is important to seek out specialists who have appropriate experience in its treatment and care – usually with referral to neurological services at the Lancashire and South Cumbria Motor Neurone Disease Care and Research Centre in Preston.

Some people also experience changes to their thinking and behaviour. However, Motor Neurone Disease affects everyone differently. Not all symptoms will affect everyone, or in the same order. Symptoms also progress at varying speeds, which makes the course of the disease difficult to predict. You can watch a video on Motor Neurone Disease [here](#).

There is a 1 in 300 risk of getting Motor Neurone Disease across a lifetime. It can affect adults of any age but is more likely to affect people over 50. You can read more about Motor Neurone Disease statistics [here](#).

The five points of the Motor Neurone Disease Charter are:

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

Since the launch of this campaign in March 2016, [80 councils have adopted the MND Charter](#).

Councils play a key role in delivering various services highlighted in the Motor Neurone Disease Charter, so by speaking to councillors, campaigners raise awareness of Motor Neurone Disease at a local level and help to create change for those living with Motor Neurone Disease by encouraging the council to adopt the Charter and to work in partnership with us to improve services for people with Motor Neurone Disease.

Supporting this adoption is the Lancashire and South Cumbria Motor Neurone Disease Care and Research Centre team, based at Royal Preston Hospital, who provide monitoring, support, guidance and advice to people who have been diagnosed with Motor Neurone Disease and their families in Lancashire & South Cumbria.

The nurse-led Motor Neurone Disease team work closely with the consultant neurologists to provide timely diagnosis and ongoing care, providing three monthly reviews, either at local hospices or at home.

The Motor Neurone Disease team work also closely with the Motor Neurone Disease Association and liaise with many health and social care professionals to provide co-ordination and reduce overlap in services, offering bespoke education sessions for those with little experience in this complex condition.

The Motor Neurone Disease team work closely with the research department to facilitate participation in research and drug trials and are delighted to be one of six collaborating centres in the UK to be involved in ENCALS (European Network to Cure ALS).

List of background papers

Packs of Motor Neurone Disease Charter resources will be available to all members on the day and after adoption a pack of MND Charter post adoption resources will be provided by the Motor Neurone Disease Association as well as a framed certificate and a template press release.

[What is the MND Charter?](#)

[The MND Charter](#)

[Guide to MND for Councillors](#)

[Campaign Guide for Councillors](#)

[Bringing the MND Charter to Life](#)