

<b>HEALTH AND WELLBEING BOARD</b>			
<b>Report Title</b>	Intention to Sign the Motor Neurone Disease Charter		
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<b>Class</b>	Part 1 (Open)	Date:	11 <sup>th</sup> July 2019

## 1. Purpose

- 1.1 Councillors were first approached by a resident of Lewisham in 2016 to request that they consider signing up to the Motor Neurone Disease Charter.
- 1.2 Following discussion with partners (including the Clinical Commissioning Group) this report sets out the intention of the London Borough of Lewisham, Lewisham CCG, South London and Maudsley Trust (SLAM) and Lewisham and Greenwich Trust (LGT) to collectively sign up to the MND Charter.

## 2. Recommendations

- 2.1 It is recommended that the Health and Wellbeing Board:
  - Agree to endorse the MND Charter and work towards its vision.
  - Task the healthcare partners with collective delivery of the aims within the Charter and receive an update on progress in due course.

## 3. Background

- 3.1 MND is a fatal, rapidly progressing disease that affects the brain and spinal cord. It can leave people locked in a failing body, unable to move, talk and eventually breathe. It kills around 30% of people within 12 months of diagnosis and more than 50% within two years. It affects people from all communities and there is no cure.

## 4. The MND Charter

- 4.1 The MND Charter has been developed by the Motor Neurone Disease Association (Charitable Organisation). It is a statement of the respect, care and support that people living with motor neurone disease and their carers should expect.
- 4.2 The Charter consists of 5 Quality Statements and an explanation of the “evidence” that would indicate that each Statement is being met. The Statements are:

- i. People with MND have the right to early diagnosis and information
- ii. People with MND have the right to high quality care and treatments
- iii. People with MND have the right to be treated as individuals and with dignity and respect
- iv. People with MND have the right to maximise their quality of life
- v. Carers of people with MND have the right to be valued, respected, listened to and well supported.

## **5. Implementation of the Charter**

- 5.1 In signing the Charter, partners are committing to undertake the work required to assess the current service provision, how it's coordinated and take steps to address identified areas for improvement.
- 5.2 The Charter sets out the key services that commissioning bodies will need to work with to ensure that Lewisham is working towards the Quality Standards.

These include:

- Neurology
  - Primary Care
  - Motor Neurone Disease Association
  - Palliative Care
  - Respiratory Service
  - Dietetics
  - Pharmacy (Medicine Management)
  - Continuing Healthcare Team
  - Social Care
  - Speech and Language Therapy
  - Augmentative and Alternative Communication (Assessment and Provision)
  - Research Bodies
  - Housing (includes Home Adaptations)
  - Wheelchair Services
  - Benefits Advice
  - Carers Services
- 5.3 Officers will initiate a self-assessment to ascertain the current provision for those people living in Lewisham with a diagnosis of MND (and their families) and identify where there are gaps and areas for improvement.
  - 5.4 Lewisham Public Health will be approached to assist with identifying the number of Lewisham residents affected by Motor Neurone Disease, so that we can begin mapping out pathways and exploring whether a joined up approach across SE London would be more effective. As the main centre for the diagnosis and treatment of MND is based at King's College Hospital, this may be more appropriate.

- 5.5 Any service implications and financial considerations will need to be taken into account when determining areas for improvement and plans to address them. This may impact on timescales and areas may need to be prioritised. It should also be recognised that choice of service may be limited due to some of them being of a specialist nature.

## 6. Conclusion

Lewisham Healthcare Partners are fully committed to ensuring that residents living with MND, and their families, get the right care and support at the right time. This care should be of high quality and ensure that people with MND have as high quality of life as possible and are able to die with dignity.

Due to the wide range of services involved in the care and support required, a partnership approach to agreeing prioritised actions and monitoring implementation will be essential. Therefore, it is recommended that the Lewisham Health and Wellbeing Board continues to receive updates and monitor the progress towards achieving the Motor Neurone Disease (MND) Charter.

If there are any queries on this report, please contact Corinne Moocarme, Joint Commissioning Team on 020 8314 3342. [corinne.moocarme@nhs.net](mailto:corinne.moocarme@nhs.net)

### Background Documents:

The MND Charter – MND Association (2014)  
[www.mndassociation.org/charter](http://www.mndassociation.org/charter)

NICE Guideline (NG42) – Motor Neurone Disease Assessment and Management – February 2016