



Although a formal committee of the city council, the Health & Wellbeing Board has a remit which includes matters relating to the Clinical Commissioning Group (CCG), the Local Safeguarding Board for Children and Adults as well as Healthwatch. Papers come from a variety of sources. The format for Health & Wellbeing Board papers is consequently different from papers submitted to the city council for exclusive city council business.

1. Motor Neurone Disease (MND) Charter

- 1.1. The contents of this paper can be shared with the general public.
- 1.2 This paper is for the Health & Wellbeing Board meeting on the 12th July 2016.
- 1.3 Author of the Paper and contact details
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2. Summary

- 2.1 The Motor Neurone Disease Association (MNDA) has recently published an MND Charter which it is asking Local Authorities to adopt. The MND Charter is included for reference as Appendix 1 to this report.

3. Decisions, recommendations and any options

- 3.1 That the Board agrees to adopt the MND Charter (**Appendix 1**).



4. Relevant information

4.1 The MND Charter has five points:

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

4.2 The MND Association has asked Local Authorities to adopt the MND Charter. In Brighton & Hove, officers of both the city council and the CCG have confirmed that the standards of care for people with MND and their families and carers, that are demanded by the charter tally with our commissioning intentions. Formal approval of the charter has been delegated to the Health & Wellbeing Board as the council and CCG partnership body for the city.

4.3 More information on Motor Neurone Disease and the MND Charter can be found here: <http://www.mndcharter.org>

5. Important considerations and implications

Legal:

5.1 The adoption of the charter will assist relevant public bodies to fulfil their legal and regulatory duties to people with MND and their families and carers.

Lawyer consulted: Natasha Watson Date: 30.06.16

Finance:

5.2 There are no financial implications as a direct result of the recommendations of this report. Services for people with MND are funded from within the physical support budget.

Finance Officer consulted: David Ellis Date: 29/06/16

Equalities:



5.3 None identified

Sustainability:

5.4 None identified.

Health, social care, children's services and public health:

5.5 None identified.

6. Supporting documents and information

6.1 Motor Neurone Disease Charter (**Appendix 1**)

