

HEALTH AND WELLBEING BOARD		AGENDA ITEM No. 5
23 MARCH 2017		PUBLIC REPORT
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MOTOR NEURON DISEASE CHARTER

RECOMMENDATIONS	
FROM : Motor Neuron Disease Association	Deadline date : N/A
<ol style="list-style-type: none"> 1. The Health and Wellbeing Board to note the Motor Neuron Disease (MND) Charter (attached at Appendix 1) which was adopted by Peterborough City Council at its meeting on 8 March 2017. 2. The Health and Wellbeing Board to discuss ways in which support services are able to work better together to improve the lives of those living with MND: to breathe life into the Charter so it makes a real difference in improving the health and wellbeing of people with MND and to find a way to co-ordinate the numerous health and social care functions to provide an appropriate level of respect, care and support for those living with the disease. 	

1. ORIGIN OF REPORT

- 1.1 This report is submitted to the Board from Daniel Emery, representing the Motor Neuron Disease Association, as their volunteer Campaign Coordinator for Cambridgeshire.

2. PURPOSE AND REASON FOR REPORT

- 2.1 MND is a complex disease and challenging to manage for health and social care professionals. Given Peterborough City Council adopt the MND Charter, to avoid it becoming little more than a gesture to current and future people living with MND, the intention of this report is to ignite discussion on how best to move forward in implementing the Charter so that it makes a real difference to real people's lives.
- 2.2 This report is for Board to consider under its Terms of Reference No. 2.2 *To actively promote partnership working across health and social care in order to further improve health and wellbeing of residents.*

3. Background

3.1 About MND

- MND is a fatal, rapidly progressing disease that affects the brain and spinal cord.
- It attacks the nerves that control movement so muscles no longer work.
- It leaves people locked in a failing body, unable to move, talk and eventually breathe.
- It kills a third of people within a year and more than half within two years of diagnosis.
- It affects up to 5,000 adults in the UK at any one time. The Association is aware of **people** living with MND in Peterborough and the surrounding areas.
- It has no cure

3.2 About the Charter

The MND Charter is a statement of the respect, care and support that people living with MND and their carers deserve and should expect. The five points of the Charter are:

- 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

3.3 Improvement Opportunities

Based on my personal observations as we care for our father who lives with MND, and feedback from other people living with MND in Peterborough and the surrounding area, some of the improvement opportunities include the following: -

- Coordinating care for MND and other rare diseases so services are no longer disjointed and provided in a timely manner
- A better understanding of MND – specifically the speed of progression and how the individual's social and care needs change significantly
- Improved communication between services providers e.g. Adult Social Care and NHS
- Ensuring outsourced care providers are appropriate
- Ensuring hospital admission and discharge is timely
- Arranging appropriate care and equipment as the disease progresses
- Joint working with children's services where people with MND has children – specifically support or help with planning
- Limited support for people caring for people with the disease
- Ensuring housing adaptations and rehousing is timely and planned as opposed to reacting to emergency situations
- Raising the knowledge of MND amongst OTs
- Providing funded day care or palliative day care

4. CONSULTATION

4.1 Minimal consultation has taken place to date as the MND Charter has only just recently been adopted by Peterborough City Council. Thus far discussion has been limited to Alan Dowson (Councillor sponsoring the MND Charter) and Stewart Jackson MP.

4.2 My intention would be to seek guidance from the Board on the scope of future discussions/consultations that should take place, following the recent adoption of the MND Charter by Peterborough City Council.

5. ANTICIPATED OUTCOMES

The consideration for the Board is to think-through ways in which support services are able to work better together to improve the lives of those living with MND: to breathe life into the MND Charter so it makes a real difference.

6. REASONS FOR RECOMMENDATIONS

It is not clear at this stage what recommendations should be made. Evidence underlining the need for service improvement is provided in section 3.3 above.

7. ALTERNATIVE OPTIONS CONSIDERED

The obvious alternative is to do nothing i.e. keep things as they are with no change. The natural consequence is people living with MND (and their families) have reduced quality of life.

8. IMPLICATIONS

See section 6.

9. BACKGROUND DOCUMENTS

None.

10. Appendix 1 – MND Charter

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