

**TO: EXECUTIVE
6 JUNE 2017**

**MOTOR NEURONE DISEASE CHARTER
Director of Adult Social Care, Health and Housing**

1 PURPOSE OF REPORT

- 1.1 To provide the Executive with an understanding of Motor Neurone Disease (MND) and the nationally approved MND Charter, which each local authority is being asked to adopt.

2 RECOMMENDATION

- 2.1 **That the Executive Endorse Bracknell Forest Council becoming an adopter of the MND charter.**

3 REASONS FOR RECOMMENDATION

- 3.1 A national charter for MND has been published by the Motor Neurone Disease Association, which encourages local authorities to sign up to and adopt the MND Charter. The charter helps Local Authorities and communities better understand the needs of people with MND.

4 ALTERNATIVE OPTIONS CONSIDERED

- 4.1 Not applicable.

5 SUPPORTING INFORMATION

- 5.1 There are 5 points to the charter:

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.

- 5.2 Why is the MND Association approaching Council's?

The MND association acknowledges that many decision about services used by people with MND, such as social care, housing adaptations and support for carers, are made at the local level by council's and there are significant differences in the quality of services available to people with MND across the country, depending on where they happen to live.

As such, it is felt important that council and councillors understand the needs of people with MND and their carers.

5.3 What will it achieve?

By forming a partnership between the MND Association and the Local Authorities, awareness internally and ultimately externally will be achieved for people living with the disease. As councillors are key decision makers within the local authorities it is hoped by raising the profile and by providing tools for council's and councillor's when decision are made they think about the impact on people living with MND and their carers in the community.

As the focus of this campaigning is local, the specific outcomes will depend on how we wish to approach it in Bracknell Forest. It would be sensible to have a launch of the charter in collaboration with our communication team with the potential to take to the Health and Wellbeing Board at a future date.

5.4 The proposal to join the charter was raised at the Long Term Conditions and Sensory Needs Strategy Group on 30th November 2016. The group were encouraged by the charter and would like to recommend that Bracknell Forest Council signs the charter.

5.5 The purpose is to ensure that everyone understand and respect the rights of people with MND and for us as a local authority and health to understand what we may need to consider when providing care and support directly but also when commissioning services.

5.6 We are fortunate in Bracknell Forest Council to have a named lead professional (Tina Payne) for the care of people with MND. Although the numbers are low, 3 – 6 per year, the support required is intensive and follows a different approach. For example, MND is life limiting and the decline for the individual is extremely rapid. It is important to be planning for the future decline in a sensitive manner which means the individual is able to be in control, supported by us. Contingency planning and forward thinking are key aspects to the approach.

5.7 The work in Bracknell has often been held as a beacon of best practice, and so it would be fitting for us to sign up to the Charter. There are no issues in terms of whether we are achieving the goals set out in the 5 standards.

5.8 By adopting the charter, there are gains for the Local Authority. This includes access to promotional material as well as information to better inform our councillors in the event that they meet a constituent with MND.

6. **ADVICE RECEIVED FROM STATUTORY AND OTHER OFFICERS**

Borough Solicitor

6.1 There are no legal implications.

Borough Treasurer

6.2 There are no financial implications.

Equalities Impact Assessment

6.3 Not applicable.

Strategic Risk Management Issues

6.4 Not applicable.

7 CONSULTATION

Principal Groups Consulted

7.1 Long Term Conditions and Sensory Needs Strategy Group

Method of Consultation

7.2 Not applicable.

Representations Received

7.3 Not applicable.

Background Papers

MND Charter

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