

**REPORT OF CHAIRMAN OF ADULT SOCIAL CARE AND PUBLIC HEALTH  
COMMITTEE****APPROVAL FOR ADOPTION BY THE COUNCIL OF THE MOTOR NEURONE  
DISEASE CHARTER****Purpose of the Report**

1. The report requests that the Council adopts the Motor Neurone Disease (MND) Charter.

**Information and Advice**

2. Motor neurone disease is a rare condition that progressively damages parts of the nervous system. This leads to muscle weakness, often with visible wasting. Also known as amyotrophic lateral sclerosis (ALS), it occurs when specialist nerve cells in the brain and spinal cord called motor neurones stop working properly. Motor neurones control important muscle activity, such as gripping, walking, speaking, swallowing and breathing.
3. Motor neurone disease affects around two in every 100,000 people in the UK each year. There are about 5,000 people living with the condition in the UK at any one time. The condition can affect adults of all ages, including teenagers, although this is extremely rare. It is usually diagnosed in people over 40, but most people with the condition first develop symptoms in their 60s. It affects slightly more men than women.
4. Motor neurone disease is a severely life-shortening condition for most people. Life expectancy for about half of those with the condition is three years from the start of symptoms. However, some people may live for up to 10 years, and in rarer circumstances even longer. There is currently no cure for the disease. Treatment aims to make the individual feel comfortable and have the best quality of life possible, and compensate for the progressive loss of bodily functions such as mobility, communication, swallowing and breathing.
5. With strong community and specialist support, many people can maintain some independence for a significant part of the condition's course.

**The Charter**

6. The Motor Neurone Disease Charter was launched by the Motor Neurone Disease Association (MNDA) in June 2012. It is described as ‘a statement of the respect, care and support that people living with MND and their carers deserve and should expect.’
7. 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.
8. A copy of the full charter is attached to the report as an appendix.
9. Many councils have been approached to adopt the Charter. At present in the region of 50 councils have adopted it.
10. The MNDA states that the Charter was created to help raise awareness and to campaign to improve services for people with MND and their carers at the local level, in recognition of the fact that many decisions about services used by people with MND, such as social care, housing adaptations and support for carers, are made at the local level by councils. The Association believes that there are significant differences in the quality of services available to people with MND locally, depending on where they happen to live. Their aim is to ensure that every time a council makes a decision they have thought about the impact on people living with MND and their carers in the community.

### **Implications of adopting the MND Charter**

11. Much of the detail behind the points of the Charter deal with operational issues for the delivery of health care, such as access to diagnosis and specific drugs. However, the overall approach which the Charter promotes – and specifically the issues for social care – are consistent with the principles by which the Council aims to work when providing care and support to people with disabling conditions generally. They are also reflected in the provisions of the Care Act 2014, particularly in respect of information, needs assessment, carers’ rights and personalised care.
12. Whilst these principles apply broadly, the specific nature of this condition and the speed with which needs develop and become more complex make timely, person-centred and co-ordinated support particularly important in ensuring quality of life for people living with MND and their carers.
13. Councils have a role in a number of the issues addressed in the Charter including:
  - timely and appropriate information
  - early referral to social care services
  - a personal care plan
  - timely and appropriate access to equipment
  - access to respite care, and

- ensuring carers understand their legal entitlement to a Carer's Assessment and receive support in a timely way.

14. As stated above, the principles and the approach promoted in the MND Charter are consistent with the way the Council aims to provide advice, care and support to adults with a disability and long term health conditions, so adoption of the Charter does not require a significant change in the Council's overall approach.

15. It is proposed that the Charter and supporting information produced by the Motor Neurone Disease Association are shared with all elected Members and staff to raise awareness and promote the adoption of the Charter and its principles.

### **Other Options Considered**

16. To not adopt the Charter but as identified above the approach in the Charter is consistent with the principles by which the Council aims to work with all people who have disabilities and require care and support.

### **Reason/s for Recommendation/s**

17. It is recommended that the Council supports adoption of the MND Charter in recognition of the specific nature, speed of progression and impact of Motor Neurone Disease which means it is particularly important to ensure appropriate support is provided as soon as possible.

### **Statutory and Policy Implications**

18. This report has been compiled after consideration of implications in respect of crime and disorder, data protection and information governance finance, human resources, human rights, the NHS Constitution (public health services), the public sector equality duty, safeguarding of children and adults at risk, service users, smarter working, sustainability and the environment and where such implications are material they are described below. Appropriate consultation has been undertaken and advice sought on these issues as required.

### **Financial Implications**

19. There are no financial implications for the Council of adopting the MND Charter.

### **Human Resources Implications**

20. There are no specific implications for Human Resources.

### **Human Rights Implications**

#### **Implications for Service Users**

21. Adoption of the Charter will promote awareness and understanding of Motor Neurone Disease amongst elected Members and staff across the Council. This will help to ensure that people with MND and their carers and families receive appropriate support from the Council that will make a positive difference to their lives.

## **RECOMMENDATION/S**

- 1) That the Council adopts the Motor Neurone Disease Charter.

**Councillor Stuart Wallace**  
**Chairman of the Adult Social Care and Public Health Committee**

**For any enquiries about this report please contact:**

**Jennie Kennington**

**Senior Executive Officer**

**Email: [jennie.kennington@nottsc.gov.uk](mailto:jennie.kennington@nottsc.gov.uk)**

### **Constitutional Comments (LMc 05/12/17)**

22. The Policy Committee is the appropriate body to consider the contents of the report.

### **Financial Comments (KAS 11/12/17)**

23. The financial implications are contained within paragraph 19 of the report.

### **Background Papers and Published Documents**

Except for previously published documents, which will be available elsewhere, the documents listed here will be available for inspection in accordance with Section 100D of the Local Government Act 1972.

- None

### **Electoral Division(s) and Member(s) Affected**

- All