

HAMPSHIRE COUNTY COUNCIL

Decision Report

Decision Maker:	Executive Member for Adult Social Care and Health
Date:	22 November 2017
Title:	Motor Neurone Disease Charter
Report From:	Director of Adults' Health and Care

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1. Executive Summary

1.1. The purpose of this paper is to seek Executive Member endorsement and support of the principles in the Motor Neurone Disease (MND) Charter.

1.2. This paper seeks to

- Outline the standards and expectations of the MND Charter
- Outline how the MND Charter links with the County Council Strategic Plan

2. Contextual information

2.1. Motor neurone disease is fatal and rapidly progressing, with no current cure. It describes a group of related diseases, affecting the motor nerves or neurones in the brain and spinal cord, which pass messages to the muscles telling them what to do.

2.2. Degeneration of the motor neurones leads to weakness and wasting of muscles, causing increasing loss of mobility in the limbs, and difficulties with speech, swallowing and breathing. Approximately one third of people die within a year of diagnosis and more than half within two years of diagnosis.

2.3. The Motor Neurone Disease Association has developed a Charter (Appendix 1) for people and organisations that have contact with sufferers of the disease, which sets out standards and expectations in five key areas.

2.5 The five areas within the MND Charter are in line with the way that the council seeks to support people, and their families and carers with complex conditions. By supporting and endorsing the principles Hampshire County Council will be making a clear and public commitment to the standards within the MND Charter that relate to adult social care and by working with its partners to do so.

3. The Motor Neurone Disease Charter

3.1. The Motor Neurone Disease Association (MNDA) is the only national charity in England, Wales and Northern Ireland focused on MND care, research and campaigning.

3.2. The MNDA have developed a MND Charter setting out how everyone with a connection to MND, either personally or professionally, should recognise and respect the rights of people with MND, and work towards the Charter's vision of the right care, in the right place at the right time. The Charter can be found at Appendix 1.

3.3. The MND Charter is divided into five areas:

People with MND have the right to an early diagnosis and information

- An early referral to a neurologist.
- An accurate and early diagnosis, given sensitively.
- Timely and appropriate access to information at all stages of their condition.

People with MND have the right to high quality care and treatments

- Access to co-ordinated multidisciplinary care managed by a specialist key worker with experience of MND.
- Early access to specialist palliative care in a setting of their choice, including equitable access to hospices.
- Access to appropriate respiratory and nutritional management and support, as close to home as possible.
- Access to the drug Riluzole.
- Timely access to NHS continuing healthcare when needed.
- Early referral to social care services.
- Referral for cognitive assessment, where appropriate.

People with MND have the right to be treated as individuals and with dignity and respect

- Being offered a personal care plan to specify what care and support they need.
- Being offered the opportunity to develop an Advance Care Plan to ensure their wishes are met, and appropriate end-of-life care is provided in their chosen setting.
- Getting support to help them make the right choices to meet their needs when using personalised care options.
- Prompt access to appropriate communication support and aids.
- Opportunities to be involved in research if they so wish.

People with MND have the right to maximise their quality of life

- Timely and appropriate access to equipment, home adaptations, environmental controls, wheelchairs, orthotics and suitable housing.
- Timely and appropriate access to disability benefits.

Carers of people with MND have the right to be valued, respected, listened to and well supported.

- Timely and appropriate access to respite care, information, counselling and bereavement services.
- Advising carers that they have a legal right to a Carer's Assessment of their needs, ensuring their health and emotional well being is recognised and appropriate support is provided.
- Timely and appropriate access to benefits and entitlements for carers.

3.4 There are some areas of the MND Charter which are within the influence of our partner organisations, such as the Health Service and District and Borough Councils. However all five areas of the Charter are consistent with the way that the council seeks to work with its partners to support Hampshire residents in a personalised, dignified way, that helps people to experience the best quality of life possible.

3.5 The Council has a clear role to play in the support of people with MND who are eligible for social care services and can work with its partners toward the aims set out in the Charter.

3.6 Encouraging local authorities to sign up to the MND Charter is part of the current phase of the MND Association's National Campaign, which seeks to positively influence outcomes for people in local communities who have MND. A number of other councils have already signed up to the Charter, including Oxford, Surrey and Portsmouth and Southampton City Council's.

4. Finance

4.1. There are no financial implications in supporting and endorsing the principles of this Charter.

5. Legal Implications

5.1. Under the Care Act 2014 the Council has a duty to assess any adult who may have needs for care and support. Subject to eligibility criteria being met, the Council must then consider what can be done to meet any identified eligible needs. The Charter itself has no legal implications for the Council.

6. Consultation and Equalities

6.1. An EIA has not been carried out for this decision, as endorsing the principles of the Charter shows a commitment from the council to meet the positive outcomes outlined for people with MND in the MND Charter. This does not signify a change in council policy; the outcomes align with the current aims of the County Council for people with complex conditions.

6.2. The County Council will include reference to its support for the principles of the Charter in appropriate pan-organisational communications.

7. Recommendation

- 7.1. That the Executive Member for Adult Social Care and Health support and endorse the principles set out in the MND Charter on behalf of Hampshire County Council.

CORPORATE OR LEGAL INFORMATION:**Links to the Strategic Plan**

Hampshire maintains strong and sustainable economic growth and prosperity:	no
People in Hampshire live safe, healthy and independent lives:	yes
People in Hampshire enjoy a rich and diverse environment:	no
People in Hampshire enjoy being part of strong, inclusive communities:	yes

Section 100 D - Local Government Act 1972 - background documents

The following documents discuss facts or matters on which this report, or an important part of it, is based and have been relied upon to a material extent in the preparation of this report. (NB: the list excludes published works and any documents which disclose exempt or confidential information as defined in the Act.)

Document

Location

None

IMPACT ASSESSMENTS:

1. Equality Duty

1.1. The County Council has a duty under Section 149 of the Equality Act 2010 ('the Act') to have due regard in the exercise of its functions to the need to:

Eliminate discrimination, harassment and victimisation and any other conduct prohibited under the Act;

Advance equality of opportunity between persons who share a relevant protected characteristic (age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, gender and sexual orientation) and those who do not share it;

Foster good relations between persons who share a relevant protected characteristic and persons who do not share it.

Due regard in this context involves having due regard in particular to:

The need to remove or minimise disadvantages suffered by persons sharing a relevant characteristic connected to that characteristic;

Take steps to meet the needs of persons sharing a relevant protected characteristic different from the needs of persons who do not share it;

Encourage persons sharing a relevant protected characteristic to participate in public life or in any other activity which participation by such persons is disproportionately low.

1.2. Equalities Impact Assessment:

An EIA has not been carried out for this decision, as endorsing the principles of the Charter shows a commitment from the council to meet the positive outcomes outlined for people with MND in the MND Charter. This does not signify a change in council policy; the outcomes align with the current aims of the County Council for people with complex conditions.

2. Impact on Crime and Disorder:

2.1. No impact has been identified

3. Climate Change:

a) How does what is being proposed impact on our carbon footprint / energy consumption?

No impact has been identified

b) How does what is being proposed consider the need to adapt to climate change, and be resilient to its longer term impacts?

No impact has been identified