



Doncaster Council

Report

Date: 19 June 2018

To the
Cabinet Member for Adult Social Care

MOTOR NEURONE DISEASE CHARTER

Relevant Cabinet Member(s)	Wards Affected	Key Decision
Cllr Rachael Blake	All wards	No

EXECUTIVE SUMMARY

1. The purpose of this paper is to seek endorsement and support of the principles in the Motor Neurone Disease (MND) Charter and to adopt the charter locally in Doncaster. The paper seeks to:
 - Outline the standards and expectations of the MND Charter
 - Outline how the MND charter links with the Doncaster Growing Together plan

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

The MNDA have developed an MND (motor neurone disease) 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. The charter can be found at *Appendix 1*.

The MND charter has identified 5 key areas:

- 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 supported.

The five areas of the charter are in line with the Council's corporate priorities and support the themes in the Doncaster Growing Together plan, the Health and Wellbeing strategy, the Place plan and the adult and social care transformation agenda.

EXEMPT REPORT

2. There are no exemptions in this report.

RECOMMENDATIONS

3. To support and endorse the principles set out in the MND charter on behalf of Doncaster Council and encourage that all partner organisations also sign up to it in 2018.

WHAT DOES THIS MEAN FOR THE CITIZENS OF DONCASTER?

4. All residents in Doncaster have the right to health and social care services that are easily accessible and provide the right level of care. Increasing awareness of particular life limiting conditions is also essential to ensure that residents have the right information and are given the right diagnosis in an appropriate time frame. Residents have the right to an early diagnosis and information, access to quality care and treatments and the right to be treated as individuals with dignity and respect.

An MND charter would meet that need and ensure that all organisations are signed up to meeting that need.

BACKGROUND

5. Motor neurone disease (MND) is a fatal, rapidly progressing disease that affects the brain and spinal cord. It describes a group of diseases affecting the motor nerves or neurones in the brain and spinal cord which pass messages to muscles telling them what to do and consequently attacks the nerves that control movement so muscles no longer work. There is currently no cure. MND kills a third of people within a year and more than half within two years of diagnosis. MND can leave people locked in a failing body unable to move, to talk, to swallow and eventually breathe. MND affects people from all communities and in a person's lifetime the risk of developing MND is 1 in 300 people. It affects up to 5,000 adults in the UK at any one time and on average 6 people are diagnosed every day with the same number losing their lives each and every day.

The Motor Neurone Disease Association has produced and developed a charter for people and organisations that have contact with sufferers of the disease which sets out standards and expectations in five key areas. 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 supported.

In March 2018 a local resident, Valerie Wood, spoke at the Doncaster Health and Wellbeing Board and shared her personal story around her husband's diagnosis and on-going care within Doncaster. She stated how important it was for all services to recognise the effects of the disease and how important it was for those diagnosed to receive the right diagnosis and receive the right quality of care and treatment. She had expressed disappointment from attending the Board three years previously that this had not been taken on board by all members of the Board and was asking for endorsement across all organisations to sign up to the MND Charter in Doncaster.

Since the health and wellbeing board in March 2018, there have been a number of areas of progress around this request in terms of social care in Doncaster (see *Appendix 2* for a social care update)

OPTIONS CONSIDERED

6. The following options were considered:
 - a. Adopt and endorse the MND Charter and enlist support from all key members and organisations
 - b. Not adopt the MND Charter in Doncaster

The recommended option is option **a**.

REASONS FOR RECOMMENDED OPTION

7. The health and social care of all Doncaster residents is fundamental to the growth of Doncaster economy. With an increasing ageing population and expected impact on health and social care services early intervention is essential and providing the right quality of care is also integral to a healthy and well population.

IMPACT ON THE COUNCIL'S KEY OUTCOMES

8.

	Outcomes	Implications
	<p>Doncaster Working: Our vision is for more people to be able to pursue their ambitions through work that gives them and Doncaster a brighter and prosperous future;</p> <ul style="list-style-type: none"> • Better access to good fulfilling work • Doncaster businesses are supported to flourish • Inward Investment 	<p>Early intervention and prevention through awareness raising and good quality information will help to protect the working population and keep individuals at work as long as possible.</p>
	<p>Doncaster Living: Our vision is for Doncaster's people to live in a borough that is vibrant and full of opportunity, where people enjoy spending time;</p> <ul style="list-style-type: none"> • The town centres are the beating heart of Doncaster • More people can live in a good quality, affordable home • Healthy and Vibrant Communities through Physical Activity and Sport • Everyone takes responsibility for keeping Doncaster Clean • Building on our cultural, artistic and sporting heritage 	<p>Early intervention and prevention through awareness raising and good quality information will help keep individuals as active for as long as possible.</p>
	<p>Doncaster Learning: Our vision is for learning that prepares all children, young people and adults for a life that is fulfilling;</p> <ul style="list-style-type: none"> • Every child has life-changing learning experiences within and beyond school • Many more great teachers work in Doncaster Schools that are good or better • Learning in Doncaster prepares young people for the world of work 	<p>None</p>
	<p>Doncaster Caring: Our vision is for a borough that cares together for its most vulnerable residents;</p> <ul style="list-style-type: none"> • Children have the best start in life 	<p>Early intervention and prevention through awareness raising and good quality information will help individuals to live as independent and</p>

	<ul style="list-style-type: none"> • Vulnerable families and individuals have support from someone they trust • Older people can live well and independently in their own homes 	healthy life as possible
	<p>Connected Council:</p> <ul style="list-style-type: none"> • A modern, efficient and flexible workforce • Modern, accessible customer interactions • Operating within our resources and delivering value for money • A co-ordinated, whole person, whole life focus on the needs and aspirations of residents • Building community resilience and self-reliance by connecting community assets and strengths • Working with our partners and residents to provide effective leadership and governance 	A Council that treats those with life limiting conditions fairly and provides a whole person centred approach to those affected and their carers.

RISKS AND ASSUMPTIONS

9. There are no risks associated with this report.

LEGAL IMPLICATIONS [Officer Initials HMP... Date...10.5.18.....]

10. 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.

If the council adopts the Charter it should ensure there are measures in place to comply and review its compliance to avoid challenge.

FINANCIAL IMPLICATIONS [Officer Initials HJW Date 15/05/18]

11. There are no financial implications arising as a direct result of this report.

Where there is an assessed social care need for an adult the associated costs would be found from within the usual financial resources from the Adults Health & Wellbeing Directorate current approved budget as would be the case for any adult with an assessed need.

HUMAN RESOURCES IMPLICATIONS [Officer Initials BT...Date...14/05/18]

12. There are no HR implications in relation to this decision

TECHNOLOGY IMPLICATIONS [Officer Initials...PW Date...11/05/18]

13. There are no technology implications in relation to this decision.

HEALTH IMPLICATIONS [Officer Initials...RS.....Date ...10/05/2018.....]

14. The Health implications are contained within the body of the report.

EQUALITY IMPLICATIONS [Officer Initials RS Date10/05/2018]

15. Adopting the MND charter should reduce any inequality experienced by Doncaster residents with MND.

CONSULTATION

16. The MND charter has already been presented to the Doncaster Health and Wellbeing Board on 15th March 2018 as part of the public questions section of the meeting. All Board members were supportive of its principles and endorsed its implementation across all organisations.

BACKGROUND PAPERS

17. None.

REPORT AUTHOR & CONTRIBUTORS

Louise Robson Public Health Theme Lead (Working Age and Healthy Lives)
01302 7340115 louise.robson@doncaster.gov.uk

Dr Rupert Suckling
Director of Public Health

Appendix 1: MND Charter

What is the MND Charter and why is it important?

The motor neurone disease (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:

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

Why do we need it?

People with MND and their carers commonly experience having to explain what MND is and what their needs are. This lack of knowledge and understanding, particularly amongst decision makers and health and social care professionals, can lead to people with MND experiencing problems accessing services that are responsive to their needs.

The Charter was created to help raise awareness and campaign to improve services for people with MND and their carers at the local level.

What is its aim?

To make sure everyone understands and respects the rights of people with MND and their carers so they are given the very best opportunity to access the care they need to live the highest quality of life possible, and achieve dignity in death.

Ultimately, it aims to support work towards achieving the vision of the right care, in the right place, at the right time for people with MND and their carers.

What has it achieved?

The Charter has helped raise awareness of MND and 33,630 individuals and organisations have signed up to the Charter.

It has led to work with health and social care professionals, national and local politicians and organisations, including councils, to improve services for people with MND and their carers.

Appendix 2: Doncaster's integrated response to the MND charter

Social Care Update

- **People with MND have the right to an early diagnosis and information:** All MND patients with a Doncaster GP are accepted by the NROT (Neuro Rehab Outreach Team) and stay with the team until EOL. We do work with palliative care to ensure that we meet with the patient's wishes. At an early stage Community Matron screens and identifies the patient's needs and refers to other disciplines in the team as and when they are needed. Community Matron has regular contact throughout the patient journey.
- **People with MND have the right to high quality care and treatments** The Community Matron works with the consultant, the patient, informal and formal carers and the MDT and other agencies. The team also regularly liaise with the patients GP to address issues around medication and appropriate sign posting to other services. The community matron links in with the respiratory nurse/respiratory physio at Doncaster and Sheffield. Rehab Assistant provides support with suction machines. All this is managed in out patient's homes if this is their choice. SALT within the team provide support with swallowing and nutrition in conjunction with the dieticians. OT and Psychology work to provide cognitive support and strategies to support with adjustment. The team has a meeting every two months with MND Consultant, Specialist MND Nurse and MND Regional Advisor to discuss all patients on case load.
- **People with MND have the right to be treated as individuals and with dignity and respect.** NROT is in the unique position of having integrated Health and Social Care, therefore early identification of Social Care needs can be addressed. The community Matron completes advanced directives with patients at an early stage. The vast majority of our patients choose to remain at home and we successfully support this. SALT provide support with communication, often being able to provide bespoke communication devices.
- **People with MND have the right to maximise their quality of life.** Within the team NROT has an Occupational Therapist who has responsibility for assessing for environment controls and works closely with the Barnsley assistive technology team. OT's also provide a range of equipment, some specialist and liaise with Community OTs around adaptations. The team liaises with wheelchair services and will support with assessments relating to re housing issues. Access to information around benefits is provided by the Social Care team members, via DMBC financial assessment team. The team endeavour to maximise people's access to CHC funding.

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

Patients and their carers are referred to Social Care as soon as the need for Assessment and Carers Assessments are identified. Community Matron provides information and refers to the Hospice for counselling when needed. We also have several psychologists in the team who can support in this area.

Awareness Raising

- In June 2017 a series of MND awareness messages were sent from the public health accounts in line with the national MND awareness month. Posters were displayed internally in the Civic Office.
- On 2 July there was an 'MND is pants' walk, organised by the South Yorkshire branch of the MND Association (see attached poster) that the Council promoted internally and externally.
- June 2018 is MND awareness month again this year, these details have been added to the public health communications planner.

05/02/18