

Adoption of Motor Neurone Disease Charter

Author: Heather Twine

Contact Details: heather.m.twine@gmail.com 07401240175

Cabinet Member: Cllr Christine Lawrence

Division and Local Member: Councillor Jane Lock

1. Summary

- 1.1. Motor Neurone Disease (MND) is a fatal, rapidly progressing, incurable disease. We know of 37 Somerset residents living with MND at this time. The MND Charter (shown at Appendix A) is a statement of the respect, care and support that people living with MND and their carers deserve and should expect. Over 50 local councils across England and Wales have already adopted this Charter, publicly demonstrating a commitment to support people living with MND and their carers in the area.

2. Issues for consideration / Recommendations

- 2.1. The MND Charter, created by the MND Association, has five points:
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.
- 2.2. Whilst Somerset County Council is not responsible for everything outlined here, they are a significant part of the jigsaw. When services such as social care and housing are provided in a timely person-centred way, this is hugely beneficial to the person with MND and their family. MND is a devastating, fast moving and complex disease; it's particularly difficult to manage. If you can get it right for MND, you can get it right for residents with other neurological conditions and disabilities too. The author (a Somerset resident living with MND) recommends that the Council adopt the Charter, and celebrate the adoption with a press release, on digital platforms, and/or with a reception. Postcards, leaflets, posters can be provided by the MND Association. Adoption (which has no cost) leads to communication about how together we can improve life for people with MND, their carers and families. The Association can provide training and educational resources for front line staff, talk with Health and Wellbeing Boards, advise on developments which might impact on people with MND and provide feedback about life as a Somerset resident with MND.

3. Background

- 3.1. MND describes a group of diseases that affect the nerves (motor neurones) in the brain and spinal cord that tell your muscles what to do. With MND, messages from these nerves gradually stop reaching the muscles, leading them to weaken,

stiffen and waste. MND can affect how you walk, talk, eat, drink and breathe. Some people also experience changes to their thinking and behaviour. Symptoms progress at varying speeds, which makes the course of the disease difficult to predict. MND is life-shortening and there is no cure. Although the disease will progress, symptoms can be managed to help achieve the best possible quality of life. MND can affect adults of any age, but usually when they are 50 years old or more. The disease is more common in men than women, but this evens out with age. MND affects up to 5,000 adults in the UK at any one time. This means it is considered a relatively rare disease. As such, general health and social care professionals may not see many cases of MND, so it is important to seek out specialists who do have appropriate experience in its treatment and care. This usually means referral to professionals who are linked to neurological services. Although a few people like theoretical physicist Stephen Hawking, have unusually slow progression, it kills about 30% of people within 12 months of diagnosis, more than 50% within two years. It can leave people locked within a failing body, unable to move, talk and eventually breathe. The lifetime risk of developing MND is up to one in 300. It affects people from all communities and there is no cure. The author, Heather Twine, has a rare slower progressing form of MND, called Primary Lateral Sclerosis (PLS). Read Heather's story in the attached PDF in Appendix B, as printed in the MND Association's magazine Thumbprint in their Summer 2017 edition.

- 3.2. In 2016, NICE released its clinical guideline on the assessment and management of MND. The Charter has been written with reference to this guideline. In some parts of the country the Clinical Commissioning Group (CCG) has also adopted the MND Charter. Earlier this year, in Wiltshire there was a joint adoption celebration, when County Council and CCG adopted together. Somerset CCG has not yet been approached.

4. Consultations undertaken

- 4.1. There are two Somerset Branches of the MND Association, covering the East and West parts of the county. Run entirely by volunteers, they fund raise, run support groups for people with MND, families, carers and the bereaved. They provide trained Association Visitors offering much needed care, support, respite and small grant assistance. The Branches are aware and supportive of this proposal that Somerset County Council should adopt the MND Charter.

5. Implications

- 5.1. Adoption carries no cost or risk, but offers an opportunity to show how the Council values and respects some of its most unlucky residents. Taken at face value it is a statement of support, but it opens a door to future connections which may help improve the lives of people with MND, families and carers. Post adoption actions might include prioritising grant applications from those with such rapidly progressing conditions, ensuring telephone operators are aware of how MND affects the voice, consulting the MND Association about service changes to ensure that people with MND are considered, accessing MND Association training materials and offers.

6. Background papers

- 6.1.** The full charter document on the MND Association website (Appendix A)
<http://www.mndcharter.org/wp-content/uploads/LA-Charter-brochure2.pdf>

Heather's story shown in Appendix B, as printed in the MND Association's magazine.

Summary of the Charter's progress so far.

<http://www.mndcharter.org/wp-content/uploads/MND-Charter-summary-fold-out-card.pdf>

A guide to MND for Councillors

<http://www.mndcharter.org/wp-content/uploads/Councillor-guide.pdf>

A guide to Charter adoption for Councillors

http://www.mndcharter.org/wp-content/uploads/Guide_for_councillors.pdf

Ideas for action after adoption

<http://www.mndcharter.org/wp-content/uploads/Bringing-the-MND-Charter-to-life.pdf>