

THURSDAY 11 APRIL 2019

REPORT OF THE PORTFOLIO HOLDER FOR COMMUNITIES**MOTOR NEURONE DISEASE CHARTER****EXEMPT INFORMATION**

None

PURPOSE

To consider the adoption of the Motor Neurone Disease (MND) Charter to assist in the achievement of quality of life, dignity and respect for people with MND and their carers in Tamworth.

RECOMMENDATIONS

Members are asked to support the 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.

EXECUTIVE SUMMARY

Five people a day die in the UK from MND. It is a rapidly progressive, fatal disease that can affect any adult at any time. The disease leaves people unable to walk, talk or feed themselves. The cause of MND is unknown and there is no cure. Today there are 5,000 people living with MND in the UK. Life expectancy from diagnosis is two to five years.

Over 60 Councils have already pledged nationally <http://www.mndcharter.org/> and was recommended for support by the Health and Wellbeing Scrutiny Committee on July 2018.

Support in Staffordshire is given by the Staffordshire Support Group of the MND Association <https://www.mndassociation.org/getting-support/local-support/branches/west-midlands/staffordshire-support-group/>

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 where it is within powers to do so or assist with relevant community support in order to make a positive difference to their lives.

Following adoption of the MND Charter the Council will implement the following practical actions:

- Press release and promotion on social media as per the MND guidance

- Ensure all Members, relevant staff and partners have appropriate information with regard to the Charter pledge http://www.mndcharter.org/wp-content/uploads/Guide_for_councillors.pdf – Attached as Appendix 1
- Receive updates from the MND association and circulate these to staff and elected Members as appropriate.

OPTIONS CONSIDERED

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 in accordance with Making Equalities Real in Tamworth (MERIT) policy.

RESOURCE IMPLICATIONS

None identified and actions arising are noted above within current resource

LEGAL/RISK IMPLICATIONS BACKGROUND

There are no significant risks identified

The report has an Equality Impact Assessment attached as Appendix 2.

SUSTAINABILITY IMPLICATIONS

Information will regularly be received to ensure awareness in all matters is considered moving forward and support meets Council priorities and resource.

The Council will continue to review all ongoing requests from support organisations on a proportional basis with due consideration for impact on the organisation.

BACKGROUND INFORMATION

Launched in June 2012 by the Motor Neurone Disease (MND) Association, the five-point MND Charter sets out the rights of people with MND and their carers.

The five points are:-

1. People with MND have the right to an early diagnosis and information
2. People with MND have the right to access quality care and treatments
3. People with MND have the right to be treated as individuals and with dignity and respect
4. People with MND have 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

MND attacks the nerves that control movement; people with MND can still think and feel, but their muscles refuse to work. As these nerves die, the muscles weaken and waste, leaving people locked in a failing body, unable to move, walk or talk.

The MND Association is the only national charity in England, Wales and Northern Ireland that funds and promotes global research into the disease and provides care and support for people affected by MND.

The approach is not unique and the Council currently support the Dementia Action Alliance and have signed up to the Armed Forces Covenant.

REPORT AUTHOR

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LIST OF BACKGROUND PAPERS

None

APPENDICES

Appendix 1 – Guide for Councillors which includes the MND Charter
Appendix 2 – Equality Impact Assessment

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