

Name of meeting: Council
Date: 18th March 2020
Title of report: Motor Neurone Disease Charter

Purpose of report:

Council is asked to sign up to the Motor Neurone Disease Charter and encourage local NHS partners to do likewise to ensure a fully integrated approach across Kirklees and West Yorkshire.

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| Key Decision - Is it likely to result in spending or saving £250k or more, or to have a significant effect on two or more electoral wards? | No |
| Key Decision - Is it in the <u>Council's Forward Plan (key decisions and private reports)?</u> | Key Decision – No Private Report/Private Appendix – No |
| The Decision - Is it eligible for call in by Scrutiny? | Yes |
| Date signed off by <u>Strategic Director</u> & name | Richard Parry - 6 th January 2020 |
| Is it also signed off by the Service Director for Finance? | Eamonn Croston - 6 th January 2020 |
| Is it also signed off by the Service Director for Legal Governance and Commissioning? | Julie Muscroft - 6 th January 2020 |
| Cabinet member <u>portfolio</u> | Cllr Khan, Health and Social Care |

Electoral wards affected: All

Ward councillors consulted: No

Public or private: Public

Has GDPR been considered? Yes

1. Summary

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. Council is asked to sign up to the Charter and encourage local NHS partners to do likewise to ensure a fully integrated approach across Kirklees, as part of our shared commitment to improving health and care support for those who need it most.

2. Information required to take a decision

MND Charter

MND is a fatal, rapidly progressing disease that affects the brain and spinal cord. It attacks the nerves that control movement, so muscles refuse to work. A third of people with MND die within a year of diagnosis, and more than half within two years. It kills six people per day in the UK and affects up to 5,000 adults at any one time. Unfortunately, there is no cure.

Adopting the MND Charter (See Appendix 1) is a powerful way of supporting people with MND in our community. Nearly 90 Councils across the country, including all our neighbouring Councils, have already adopted the Charter. By adopting the Charter Kirklees would be sending a strong message to local people with MND and their carers that we hear their voices and are working hard to ensure they are valued, respected, and well supported.

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.

While councils are not responsible for everything outlined in the MND Charter, 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 has a huge impact on the person with MND and their family. MND is a devastating, complex disease and particularly difficult to manage. If we can get it right for people with MND, we can get it right for residents with other neurological conditions and disabilities.

3. Implications for the Council

3.1 Working with People

A key aspect of implementing the Charter will be working closely with those affected by MND to assess our current position against the five points, and to plan how we can improve.

3.2 Working with Partners

The Charter cannot be delivered without close collaboration, especially with NHS partners and other care providers such as Locala and Kirkwood Hospice.

3.3 Place Based Working

Whilst there are opportunities to develop place based solutions within the different localities in Kirklees it will be equally important to collaborate with partners across the West Yorkshire Health and Care Partnership to ensure appropriate specialist services are available.

3.4 Climate Change and Air Quality

Maximising the support available to enable people with Motor Neurone Disease to live as independently as possible for as long as possible in their own homes should

reduce the need to travel. There is no direct link between Motor Neurone Disease and air quality.

3.5 Improving outcomes for children

Whilst MND is predominantly a condition experienced by adults, the overall improvements in care the Charter advocates would also impact on children and young people with disabilities.

3.6 Other (eg Legal/Financial or Human Resources)

Adopting the Charter is voluntary and provides an opportunity for the Council to demonstrate how it is delivering its responsibilities under the Care Act. It does not create any new legal, financial or human resource obligations that cannot be managed through existing service planning and budget processes.

4. Consultees and their opinions

All neighbouring Council's in West Yorkshire have adopted the MND Charter and seen benefits for local people with MND through promoting a more collaborative approach across partners.

The CCGs in Kirklees are supportive of the aims of the Charter and recognise the importance of collaborating through the West Yorkshire and Harrogate Health and Care Partnership to ensure appropriate specialist services are available.

5. Next steps and timelines

MND Charter

By August 2020:

- Work with partners across the Kirklees and West Yorkshire health and care system to complete a 'stocktake' of current services/practice against the five points of the Charter to identify the key improvement priorities
- Identify opportunities in existing and emerging plans to address the key improvement priorities.

By Autumn

- Develop an action plan to address any MND specific improvement priorities.

6. Officer recommendations and reasons

- That Kirklees Council signs up to the MND charter to demonstrate it's commitment to improving the lives of people living with MND and other neurological conditions and disabilities, and works with partners across Kirklees and West Yorkshire to ensure Kirklees residents are receiving the care and support they need to live as independently as possible for as long as possible.

7. Cabinet Portfolio Holder's recommendations

- That Kirklees Council signs up to the MND charter.
- That local NHS organisations are also asked to sign up to the Charter given the important role that they play in commissioning and providing services to people with MND.

8. Contact officer

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9. Background Papers and History of Decisions

The MND: Charter Achieving quality of life, dignity and respect for people with MND and their carers (Appendix 1)

10. Service Director responsible

Richard Parry, Strategic Director Adults and Health, Kirklees Council
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The MND Charter

The MND Charter is a statement of the respect, care and support that people living with motor neurone disease (MND) and their carers deserve and should expect.

1. 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.

2. 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.

3. 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.

4. 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.

5. 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.

<https://www.mndcharter.org/wp-content/uploads/LA-Charter-brochure2.pdf>