

Committee: Health and Wellbeing Board

Date: 28 November 2017

Wards: All

Subject: Motor Neurone Disease (MND)

Lead officer: Dr Dagmar Zeuner, Director of Public Health.

Lead member: Councillor Tobin Byers, Cabinet Member for Adult Social Care and Health

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Recommendations:

- A. The Health and Wellbeing Board are asked to commend the MND Charter for its work and the goals of the Charter.
 - B. To welcome progress on the actions of the Neurological Conditions Needs Assessment and agree the proposed actions/recommendations to support people with neurological conditions in Merton.
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1 PURPOSE OF REPORT AND EXECUTIVE SUMMARY

A Council resolution was made in July 2017 asking the Health and Wellbeing Board to consider adopting the MND Charter. This report briefs the Board so that they can consider the Council resolution. The report provides an update on the Long Term Neurological Health Needs Assessment (2015) and identifies services in Merton that support the MND Charter and other neurological conditions.

2 BACKGROUND

- 2.1. A Council resolution was made in July this year to 'ask Merton Health and Wellbeing Board (HWBB) to consider adopting the MND Charter, which sets out the care and support that people living with MND and their carers deserve and should expect'.
- 2.2. The resolution spoke of raising awareness of MND and demonstrating what good care looks like for those living with this devastating disease.
- 2.3. Key areas of the MND Charter include;
 - Early referral, accurate and early diagnosis and timely information
 - High quality care and treatment
 - Personal care planning
 - Access to equipment, adaptations and suitable housing
 - Access to care assessments, respite care and welfare benefits
- 2.4. In response to the request, consideration of the MND charter took place alongside a review of the Long Term Neurological Needs Assessment which was undertaken in 2015. The health, social care and housing services

that are available to support people with neurological conditions including MND (and which respond to elements of the MND Charter) were also examined.

3 DETAILS

3.1. The main findings of the Long Term Neurological conditions Health Needs Assessment (2015) regarding the prevalence of neurological conditions in Merton were:

- An estimated total of 4,626 people in Merton are living with long term neurological conditions (excluding headaches and migraine).
- An estimated 1,753 residents have essential tremor, 1,031 are estimated to have epilepsy, 412 Parkinson's disease, 384 cerebral palsy and 297 multiple sclerosis.
- The prevalence of MND in Merton was estimated to be 14 individuals in the population.¹

3.2. Motor Neurone Disease (MND) is a fatal, rapidly progressive neuroglial disease. (Appendix 2 contains further information about Motor Neurone Disease, as well as information on diagnosis and treatment).

- Data from the Primary Care Mortality Database revealed that there were 18 deaths associated with Motor Neurone Disease in Merton between 2010-2014.

3.3. The HNA reviewed services available for people with long term neurological conditions. It should be noted that commissioning responsibilities are complex with the CCG, NHS England and LB Merton commissioning a range of important services. These span a spectrum of services, from acute hospital care to social care and support for carers. These complexities stress the importance of health and social care integration, so that patients can experience a seem-less service, one of the ambitions of the Health and Wellbeing Board.

3.4. Key services outlined include;

- Specialist and general inpatient and outpatient care, specialist nursing support and community rehabilitation. In addition, palliative care, end of life care and social services support can be accessed by people with a neurological condition.
- There is an established path for epilepsy patients in place with a two year open review following diagnosis. Formal pathways are not in place for other LTNCs, however informal pathways are followed which reflect best practice guidelines.

¹ NB This figure was derived from national estimates and it is important to treat it with caution due to population variation. For instance, there are a larger number of children and young people living in Merton and fewer people aged 50 and above compared to the average national population, and MND is most common amongst individuals aged 50-70.

- Support can include carers' assessments, advice and signposting for welfare benefits and personal budgets. More detailed information is available in Appendix 3.
 - Occupational therapy provides a range of services to people with a permanent and substantial physical disability living in Merton. The service aims to help people to keep as safe and as independent as possible in their own homes. Key services include assessment; offer of services such as equipment and adaptations and Disabled Facility grants. Further information is available in Appendix 3.
 - An active voluntary sector who provide support for specific conditions.
 - Wheelchair assessment and provision are under NHS and the Wheelchair service is accessed via GP referral.
- 3.5 The HNA also highlighted gaps in service associated with long-term neurological conditions, and made recommendations to address service areas including;
- There was found to be a lack of personalised care plans across all patients with LTNCs.
 - Stakeholders and service users reported difficulty in access to Community Neurotherapy Team (CNTT) services.
 - Psychological support was consistently reported by stakeholders and service users as a gap, and it was highlighted that there was no neuropsychologist in Merton
- 3.6 The HNA also found areas where Merton was doing well including;
- Merton CCG has a slightly higher spend on neurology for marginally better outcomes.
 - Merton has a lower rate of emergency bed day use than the London benchmark for all analysed conditions.
 - The number of neurology admissions has fallen year on year since 2009/10, with the proportion of emergency admissions reducing more rapidly in Merton CCG than in London as a whole

SERVICE UPDATE SINCE THE LTNC HNA

- 3.7 Since the original Neurological Conditions Needs Assessment new work has taken place that will help to further support people with long term neurological conditions.
- 3.8 Merton CCG has commissioned a new rapid access neurology clinic, due to be launched in November 2017. Such a clinic will aid in reducing the time between GP referral and contact with a specialist, leading to early diagnosis, which is of paramount importance for certain conditions including patients with MND.

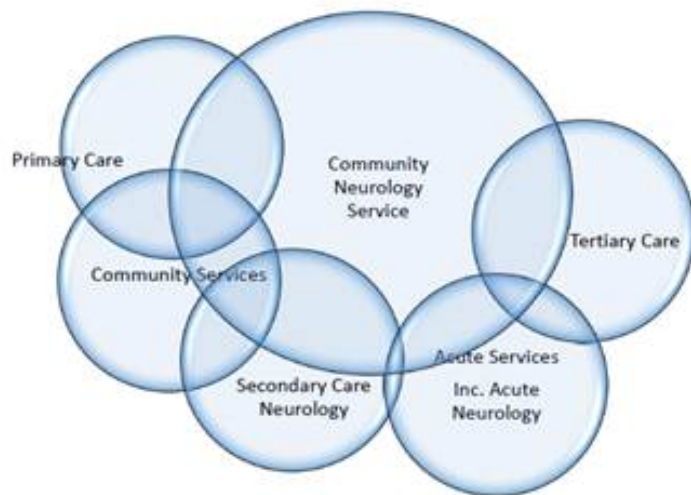


Fig 1: Venn diagram illustrating the multi-tiered coordination of the Integrated Community Neurology Provision Area.

- 3.9 The CCG is also proposing the formation of an Integrated Community Neurology Provision Area (Merton, Wandsworth, and St George’s Hospital). It will involve existing Neurology Services, (acute, primary and community) working together much more closely (initially virtually and later located in locality hub locations). The focus will be on management of long-term conditions with specialist nurse/AHP delivered services but with consultant neurologist support. This new model of care will provide appropriate levels of expertise, taking a proactive approach where high risk individuals are identified earlier through greater collaboration between primary and secondary care. The pilot for this service is expected to take place from April 2018, for a period of six months.
- 3.10 As part of these programmes of work, Merton CCG is taking into account the other gaps in service associated with long-term neurological conditions highlighted by the HNA. Examples of this include the CCG reviewing neuropsychology provision in the community team and proposing to review the current CLCH neurological conditions service specification in light of the HNA recommendations.

MND Charter

- 3.11 The Long Term Neurological Conditions Health Needs Assessment has set out the range of debilitating neurological conditions from which people living in Merton suffer. MND is a devastating condition which affects a small but significant number of people locally. The Needs Assessment set out the services in place in 2015 to support people with neurological conditions, and since that time further work has taken place and initiatives, specifically the plans of the CCG, will help to improve that support.
- 3.12 The provision identified in both the original Needs Assessment and the update conducted as part of this report addresses the goals of the MND Charter and

the HWBB commends those goals and the useful framework that they provide for assessing service provision, as well as the MND charity activity.

- 3.13 Given the HWBB statutory duty to promote the health and wellbeing of the whole population, and the range of neurological conditions which people can suffer as set out in the needs assessment, we do not think it would be appropriate to sign up to a charter specific to a single neurological condition (such as MND) . However, we do note there is further work to be undertaken on developing the support offer for people with long term neurological conditions, and the CCG will establish a reference group of service users to support this work and will report back to the HWBB in 12 months.

4 ALTERNATIVE OPTIONS

- 4.1. None.

5 CONSULTATION UNDERTAKEN OR PROPOSED

- 5.1. As part of the 2015 Assessment consultation was carried out with service users. Key themes included;
- The substantial impact of LTNCs on daily activities
 - The diagnosis process and variable degree of personalised care planning
 - Communication between professionals
 - Access to ongoing care and treatment
 - The broader needs of the individual and holistic approach necessary to care
- 5.2. In updating the Long Term Neurological Conditions Health Needs Assessment consultation took place with officers in Merton CCG, adult social care, CLHC and occupational therapy.

6 TIMETABLE

- 6.1. The timetable is as set out in the report and the full Health Needs Assessment.

7 FINANCIAL, RESOURCE AND PROPERTY IMPLICATIONS

- 7.1. None.

8 LEGAL AND STATUTORY IMPLICATIONS

None.

9 HUMAN RIGHTS, EQUALITIES AND COMMUNITY COHESION IMPLICATIONS

The Long Term Neurological Conditions Needs Assessment is aimed at understanding the real needs of those with these conditions in order to help address health inequalities.

10 CRIME AND DISORDER IMPLICATIONS

None.

11 RISK MANAGEMENT AND HEALTH AND SAFETY IMPLICATIONS

None.

12 APPENDICES – THE FOLLOWING DOCUMENTS ARE TO BE PUBLISHED WITH THIS REPORT AND FORM PART OF THE REPORT

Appendix 1 – Information on MND

Appendix 2 – Detailed service information

13 BACKGROUND PAPERS

- 14.1. Merton Long Term Neurological Conditions Health Needs Assessment 2015 available at https://www2.merton.gov.uk/merton_long_term_neurological_conditions_hna.pdf

APPENDIX 1

15. WHAT IS MOTOR NEURONE DISEASE?

16.1 Background

- 16.1 Motor neurone disease (MND) is a fatal, rapidly progressing neurological disease. It attacks the nerves that control muscle movement (motor neurones), causing them to weaken, stiffen and waste. This, in turn, leads to progressing issues with walking, speaking, swallowing and breathing.
- 16.2 Mental abilities and senses are not usually affected by MND and therefore patients generally remain aware of their deteriorating physical condition.²
- 16.3 There are different types of MND, and Amyotrophic lateral sclerosis (ALS) is the most common, accounting for up to 80% of cases.
- 16.4 We do not currently know what causes MND. Various studies have been carried out around the world and the risk of developing MND does not appear to be affected by race, diet or lifestyle. MND does not occur in epidemics, it is not infectious and it does not appear to be caused by any

² Brain Research Trust UK 2015. Accessed October 2017.

other disease. It is more common in men than women, and amongst people aged between 50 and 70 years.

- 16.5 Motor Neurone Disease affects up to 5,000 adults in the UK at any one time. MND is life-shortening, and at present, there is no cure for the disease. MND kills a third of people within a year and more than half within two years of diagnosis. ²

Diagnosis

- 16.6 MND cannot be diagnosed with one specific test and doctors will usually carry out a series of tests and investigations. Early referral from a GP to a specialist is pertinent and diagnosis is confirmed by a neurologist with the aid of a range of tests including MRI scans and nerve conduction tests.

Treatment

- 16.7 MND is an incurable condition that usually, although not always, leads to death within a few years, with a period of distressing disability preceding it. Thus, the mainstay of management is in supporting the patient, their family and carers through this process and in delivering palliative care at the appropriate juncture.
- 16.8 A multidisciplinary approach involving GPs, primary care nurses, occupational therapists, physiotherapists, speech therapists, dieticians, respite care providers, home care workers, hospital physicians and neurologists, along with many others, is likely to best serve the patient, and effective communication between all the interested parties is essential.
- 16.9 As the disease manifest itself, a patient's support needs will increase. Mobility will be reduced due to limb muscle weakness, leading to the requirement of walking aids or a wheelchair. In the later stages of MND, the muscles weaken in the chest, back and neck and people experience difficulties with swallowing and breathing. At this stage, gastrostomy tube feeding and ventilation assistance may be required.
- 16.10 Riluzole is the only drug treatment specifically for MND. Safety and efficacy of Riluzole has only been studied in ALS. Therefore, Riluzole is currently not licensed to be used in patients with any other form of motor neurone disease.
- 16.11 The effect of Riluzole is to slow the progression of symptoms of ALS, and to extend the time to mechanical ventilation. Riluzole can increase the life expectancy of people with ALS by three to six months.
- 16.12 Riluzole does not cure MND, nor can it reverse the damage already caused by the disease.
- 16.13 In Merton, Riluzole is currently commissioned and is available under shared care (i.e. shared prescribing between specialists and GPs). Access to needs-specific hospice care is a fundamental part of care for patients with life-shortening disease.

- 16.14 In Merton, St Raphael's Hospice provides services to meet the specific needs of people with Motor Neurone Disease.

APPENDIX 2

Social Care Eligibility

- 17.1 Eligibility for social care is determined through the criteria of the Care Act 2014 requiring physical or mental impairment and as a result not being able to achieve outcomes (such as personal hygiene or maintaining nutrition) which has a significant impact on the person's wellbeing. Once deemed eligible, adults including those with MND are offered needs appropriate care such as help with feeding

Carers' Assessments

- 17.2 Carers of people with MND will be eligible for a Carers' Assessment under the Care Act 2014. Where eligibility criteria for the carer are met the range of support services includes the following:
- to be granted a Carers Budget under Direct Payments (this can be used for sitting service so the informal carer can go out and the cared for person has someone to sit in with them).
 - to be granted a Carers Discretionary Grant (up to £100 for essential items such as paying for driving lessons, to pay for a microwave or pay towards a short break for the informal carer).
 - to have regular respite breaks for the cared for person.
 - to be referred to Carers Support Merton (a voluntary sector organisation, but LBM gives out a grant as well as having a contract for CSM to carry out some of the Carers Act Assessments).

Welfare Benefits

- 17.3 People with MND may need advice and information on welfare benefits. In Merton Social Services sign post customers/clients or their informal carers to either the Welfare Benefits team who support people with a range of benefit advice and applications or the Citizen Advice Bureau where the full range of benefits will be discussed.
- 17.4 Most people accessing social care, including those with MND, will usually apply for PIP (Personal Independence Payment) formerly known as Disability Living Allowance. The payment for PIP is made by the DWP (Department of Work and Pension).

Personal Budgets

- 17.5 Once the cared for person or the informal carer has been assessed as eligible for services to be funded by the local authority, then the care and support could either be met by a) commissioned services (by booking for a care provider contracted with Social Services) or b) under a Personal Budget (usually issued by Direct Payment i.e. Social Services pay an assessed amount of money to the cared for person or informal carer for them to make their own care arrangements. The Personal Budget can be used for employing a Personal Assistant (but not employing relatives living

in the same address). This gives the cared for person or informal carer more choice and control in care provisions.

Housing, Adaptations and telecare

- 17.6 Disabled facilities grants (DFGs) can be requested to help meet the cost of providing adaptations to enable people with disabilities to access their home and the facilities within it. DFGs are available to people who own their own home and private tenants.
- 17.7 Adaptation works carried out through DFGs in Merton include external ramping to entrance doors, stair lifts, level access showers and automatic toilets. An assessment must be made by a qualified Occupational Therapist to decide what works are required to meet the needs of the person with disabilities.
- 17.8 MASCOT Telecare and Community Support Services provide a range of initiatives enabling people to remain at home with independence and security. Offering care line and telecare services to vulnerable people and those with a disability, MASCOT prevents unnecessary admissions to hospital and residential care.

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