

# Health and Wellbeing Board

16 March 2017

## Motor Neurone Disease Charter



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## Report of Andrea Petty, Strategic Manager Policy, Planning and Partnerships, Durham County Council

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### Purpose of the Report

- 1 The purpose of this report is to provide the Health and Wellbeing Board with details of:
  - The Motor Neurone Disease (MND) Charter (Appendix 2).
  - Evidence of how the County Durham Health and Wellbeing Board meet the needs of people with MND and any areas for further development.

### Background

- 2 The MND Charter is part of a campaign initiated by the MND Association. They describe the MND Charter as a statement of the respect, care, and support that people living with MND and their carers deserve.
- 3 MND is a fatal, rapidly progressing disease that affects the brain and spinal cord. It can leave people locked in a failing body, unable to move, talk and eventually breathe. A person's lifetime risk of developing MND is up to one in 300. It kills around 30% of people within 12 months of diagnosis, more than 50% within two years. It affects people from all communities. It has no cure.
- 4 Nationally, the prevalence of people living with MND at any one time is approximately seven in every 100,000 people.
- 5 The MND Association believe that what matters most is that people with MND receive a rapid response to their needs and good quality care and support, ensuring the highest quality of life as possible and the ability to die with dignity. The MND Charter is intended to serve as a tool to help make this happen by supporting organisations to meet their responsibilities towards people with MND and their families and carers.

- 6 There are five commitments in the charter and evidence as to how the charter commitments are met and areas for further development are outlined below.

### **Commitments and areas for further development**

- 7 **Commitment 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.
- 8 GP's across the county are able to identify symptoms and signs of neurological problems. Plans are also in place to review neurology guidelines in line with the clinical guidelines programme of work.
- 9 Support, information, guidance and advice to people who have, or are in the process of a diagnosis is available from a variety of information sources such as health and social care staff and Locate. Locate is a free online resource offering a wealth of information, advice, and services to help people live independently and find the right care and support to meets their needs.
- 10 In addition, health and social care professionals currently attend forums with the regional clinics regarding ongoing patients/clients and the ongoing research work they undertake in relation to the condition. This work will continue to take place to develop any further links.
- 11 **Commitment 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.

- 12 Occupational Therapy staff form part of coordinated multidisciplinary teams (MDT) and already attend quarterly forums with the regional clinic and the MDT to discuss current clients and identify links and networks with other services.
- 13 End of life care is a key priority for the County Durham Health and Wellbeing Board and is identified as a strategic objective in the Joint Health and Wellbeing Strategy as follows:

“Support people to die in the place of their choice with the care and support that they need”
- 14 A Palliative and End of Life Care plan is now in place to deliver high quality sustainable services and improvements for patient and carer experience for people diagnosed with a life limiting condition. There are a number of services commissioned by CCG’s as part of the strategy which enable care closer to home including the Marie Curie Planned Nursing service and the response service which can support people with MND.
- 15 Referrals for people with MND for Continuing Healthcare (CHC) assessments are made in a timely manner if this need is identified in liaison with the CHC coordinator and support from other members of the MDT. A simple and timely process for referral to social care services is in place which can sustain the best possible quality of life.
- 16 Ongoing education for health and Social Care professionals in order to reflect advances in best practice is a potential area for development. There is an opportunity across both CCGs to use the protected learning time for GP’s for further training and within the local authority, work will take place to look to incorporate good practice briefings into the training budgets.
- 17 **Commitment 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.
- 18 All service users are involved in developing their own personal care and support plan. Personalised care is central to the care processes and full use is made of individual budgets and direct payments in support of service

users' needs and choices. The cases of people with MND are kept 'open' in recognition of the probability of rapid deterioration and therefore the need for further social care support. Occupational Therapists (OTs) will support service users to access appropriate equipment and communication aids in conjunction with NHS colleagues. The OT service will look at equipment on the commercial market if it is felt that something bespoke will meet the client needs and these clients are often referred to the NHS environmental controls service who can provide electronic assistive technology equipment on loan to severely disabled people enable them to live more independently in their homes.

- 19 The OT service will actively continue to improve their skills and knowledge to meet the needs of specialist client groups
- 20 **Commitment 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.
- 21 The OT service and the Housing providers in Durham recognise that MND is a rapidly progressive disease and work together to provide the best possible outcomes within the accommodation resources available to support the client. Fast track to adaptations can be offered should the need arise.
- 22 Specialist and non-specialist wheelchair provision is commissioned by CCG's and provided by County Durham and Darlington NHS Foundation Trust across the County. Ensuring timely access to the service is monitored as part of the contract.
- 23 A welfare rights service is in place within County Durham which ensures that service users with MND will have timely advice about disability benefits and broader welfare information.
- 24 Identified Social Care professionals will continue to work jointly with housing providers and ensure they are aware of the housing options available and the housing role.
- 25 **Commitment 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.
- 26 Each carer has a right to their own Carers Assessment and Care and Support Plan. Durham County Carers Support Service and The Bridge Young Carers Service are support services who offer information, advice and support to Carers. The services can signpost carers to welfare and benefits advice and help to access respite services and carers' breaks.
- 27 Identified Social Care professionals will continue to develop links with specialist health teams relating to MND and ensure they work together to access appropriate services in a timely manner for clients and their carers.

### **Recommendations**

28 The Health and Wellbeing Board is recommended to:

- Note how member organisations of the Health and Wellbeing Board meet the commitments to the MND Charter as outlined in this report
- Agree to adopt the MND Charter using it as a tool to progress the care and support of people with MND in the county
- Agree to receive an update on the progress of charter commitments of the Health and Wellbeing Board at a future meeting.

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**Contacts:** Jenny Warren, Strategic Commissioning Manager  
**Tel:** 07786027189  
Denise Hopper, Principal Occupational Therapist  
03000 262185

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## **Appendix 1: Implications**

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### **Finance**

Not applicable

### **Staffing**

Not applicable

### **Risk**

Not applicable

### **Equality and Diversity / Public Sector Equality Duty**

Under the Equality Act 2010 a person is classified as disabled if they have a physical or mental impairment which has a substantial and long-term effect on their ability to carry out normal day-to-day activities.

### **Accommodation**

Not applicable

### **Crime and Disorder**

Not applicable

### **Human Rights**

Not applicable

### **Consultation**

Not applicable

### **Procurement**

Not applicable

### **Disability Issues**

The Health and Wellbeing Board has been requested to adopt the MND Charter as a method of supporting people with MND, and their carers, in County Durham.

### **Legal Implications**

Not applicable