

MINUTE EXTRACT

PEOPLE OVERVIEW AND SCRUTINY COMMITTEE

28 NOVEMBER 2016

27 NOTICE OF MOTION: MOTOR NEURONE DISEASE (MND) CHARTER

The Chair of the People Overview and Scrutiny Committee reported that at the meeting of the Council held on 17 October 2016 (minute 67(1) refers), the following Notice of Motion proposed by Councillor Steve Williams and seconded by Councillor Chris Blakeley was referred by the Mayor to this Committee for consideration –

“That this Council adopts the Motor Neurone Disease (MND) Charter and thereby supports achieving quality of life, dignity and respect for people with MND and their Carers.

The Charter:

1. People with MND have the right to an early diagnosis and information.

This means:

- a) An Early referral to a Neurologist
- b) An accurate and early diagnosis, given sensitively
- c) Timely and appropriate access to information at all stages of their condition

2. People with MND have the right to access quality care and treatments.

This means:

- a) Access to co-ordinated multidisciplinary care managed by a specialist key worker with experience of MND.
- b) Early access to specialist palliative care in a setting of their choice, including equitable access to hospices.
- c) Access to appropriate respiratory and nutritional management and support, as close to home as possible.
- d) Access to the drug riluzole.
- e) Timely access to NHS continuing healthcare when needed.
- f) Early referral to social care services.
- g) Referral for cognitive assessment, where appropriate.

3. People with MND have the right to be treated as individuals and with dignity and respect.

This means:

- a) Being offered a personal care plan to specify what care and support they need.
- b) 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.

- c) Getting support to help them make the right choices to meet their needs when using personalised care options.
- d) Prompt access to appropriate communication support and aids.
- e) Opportunities to be involved in research if they so wish.

4. People with MND have the right to maximise their quality of life.

This means:

- a) Timely and appropriate access to equipment, home adaptations, environmental controls, wheelchairs, orthotics and suitable housing.
- b) 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

This means:

- a) Timely and appropriate access to respite care, information, counselling and bereavement services.
- b) 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.
- c) Timely and appropriate access to benefits and entitlements for carers."

Councillor Steve Williams tabled the Motion, and introduced Ms Debbie Williams of the Wirral MND Association who then addressed the People Overview and Scrutiny Committee.

Ms Williams expressed her thanks to all those who had responded to their recent petition, requesting adoption of the Motor Neurone Disease (MND) Charter.

Ms Williams provided Members with an explanation of the disease, which has no cure, informing that the Charter aspiration focused primarily on care and the right kind of care. She further informed that early diagnosis and the treating of those with the disease with dignity and respect went a long way to maximise the quality of life for MND sufferers and their Carers. She stated that the role of Carer was particularly difficult and should be valued and respected.

Members were apprised that the Council played a vital piece in the jigsaw in helping people to adapt and live with the disease. Ms Williams explained that by adopting the Charter, the Council would also be assisting in raising awareness of MND and helping develop to wider partnerships. Members were informed that the adoption of the Charter would also help in ensuring that the right care and support could be provided within appropriate timescales. In summary Ms Williams explained that the Wirral MND Association was structured as a small charity in Wirral, supporting people on an individual basis.

The Chair thanked the speakers and opened discussion on the subject.

A short debate took place, with the majority of Members expressing wholehearted support for the adoption of the Charter, having first-hand knowledge of the disease

either through family members, friends or relatives. There was consensus regarding the positive impact on people with MNDs dignity through home adaptations, and broader understanding of the disease and its effects on an individual's health.

A Member stated that by supporting the Charter, this could be a tremendous opportunity to work with organisations to assist those who have MND.

The Director for Health and Care informed that those eligible for Social Care will qualify, and that access to care was not disease specific. He added that MND is one of a number of long term conditions that is covered under existing protocols.

On a motion by the Chair, duly seconded it was –

Resolved - That

- 1) the Notice of Motion be supported; and**
- 2) the People Overview and Scrutiny Committee thank Mrs Debbie Williams of the Wirral Motor Neurone Disease (MND) Association for her presentation.**