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| Meeting: | Full Council |
| Date: | Monday 17th October 2016 |
| Notice of Motion: | MOTOR NEURONE DISEASE (MND) CHARTER |
| Proposed by: | Cllr. Steve Williams |
| Seconded by: | Cllr. Chris Blakeley |

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.



Cllr. Steve Williams



Cllr. Chris Blakeley