

Notice of Motion for Full Council – 19th July 2018

Motor Neurone Disease (MND) Charter

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.

Council notes that over 60 councils across the country have signed up to the Motor Neurone Disease (MND) Charter

The Charter is made up of 5 points:

1. People with MND have the right to an early diagnosis and information
2. People with MND have the right to access quality care and treatments
3. People with MND have the right to be treated as individuals and with dignity and respect
4. People with MND have 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

Motion to be moved by Councillor Julian Ware-Lane
Seconded by Councillor Tony Cox

Background:

The Motor Neurone Disease (MND) Association, five-point MND Charter sets out the rights of people with MND and their carers and the pillars of good care and support. Five people a day die in the UK from MND. It is a rapidly progressive, fatal disease that can affect any adult at any time. The disease leaves people unable to walk, talk or feed themselves. The cause of MND is unknown and there is no cure.

** MND is a fatal, neurological disease for which there is no effective treatment and no cure.*

** MND kills five people in the UK every day.*

** Today there are 5,000 people living with MND in the UK. Life expectancy from diagnosis is two to five years*

** It can affect any adult at any age. Imagine being trapped inside a body that can't move.*

** MND attacks the nerves that control movement; people with MND can still think and feel, but their muscles refuse to work. As these nerves die, the muscles weaken and waste, leaving people locked in a failing body, unable to move, walk or talk.*

Why should councils adopt the charter?

Many decisions about services used by people with MND, such as social care, housing adaptations and support for carers, are made at the local level by councillors. Currently, there are significant differences in the quality of services available to people with MND locally, depending on where they happen to live. As

such, it is important that councillors, and all those working for and with the council, understand the needs of people with MND and their carers. While councils aren't 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 a council can get it right for MND, it can get it right for residents with other neurological conditions and disabilities too.

** The MND Association is the only national charity in England, Wales and Northern Ireland that funds and promotes global research into the disease and provides care and support for people affected by MND.*