

Motor Neurone Disease (MND) Charter
Councillor Linda Hellyer

Background to the Motion

The Motor Neurone Disease Charter is a statement of respect, care and support that people living with Motor Neurone Disease (MND) and their carers deserve, and should expect.

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 1 in 300. It kills around 30% of people within 12 months of diagnosis, and more than 50% within two years. It affects people from all communities and has no cure.

Until there is a cure for MND, what matters most is that people with MND receive the right care, in the right place, at the right time to achieve the highest quality of life possible and the ability to die with dignity. The MND Charter aims to help make this happen.

There is a growing list of councils across the country who are adopting the MND Charter to demonstrate their support for local people living with this terrible disease.

The five points of the Charter are:

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

The full charter can be found at www.mndassociation.org/mndcharter

Reference to Cabinet

1. This Council adopts the Motor Neurone Disease Charter.
2. This Council encourages the District Councils in Devon to adopt the Charter.
3. This Council asks the relevant Cabinet Member(s) to ensure the Council's services and facilities are delivered in accordance with the Charter.
4. The Council's communications team promotes the adoption of the Charter, promotes how the Council's services and facilities are accessible and ensures it takes part in Purple Tuesday on 2nd November 2021.