

## **Notice of Motion for Full Council – Thursday, 17 July 2014**

**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**
- 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 Julien Parrott:**

**Seconded by Councillor Nicole Amil:**

### **Background:**

Launched in June 2012 by the Motor Neurone Disease (MND) Association, the 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.
- 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.

Councillor Parrott chose Motor Neurone Disease Association Torbay as his Chairman's charity for municipal year 2013-14. He was hugely grateful for the support of the people of the Bay and its visitors in their response to his charity and their generosity raised £4,025.00 to support local people affected by this wicked disease.