The Greater Manchester Motor Neurone Disease Care Model

**Diagnostic Pathway Including neurophysiology, scans, +/- lumbar puncture**

- Symptoms suggestive of MND
- MND diagnosed by another consultant or as an inpatient

**MND CARE CENTRE**

- Inform GP and agree shared care protocol for Riluzole
- Inform re: research opportunities and invite participation where appropriate. Encourage sign up to the MND register
- Refer to genetics services if appropriate
- Cognitive changes – refer to Cerebral Function Unit or dementia services
- Tone management + secretion management: refer to neuro-rehab specialist
- Counselling/ emotional support/carer support
- Consider alternative means to review if the patient is not able to travel to clinic eg remote clinics, outreach clinics

**MND diagnosis – patient informed and given appropriate level of information. Given Single point of care contact**

- Attend MDT MND clinic (within 4 weeks)
- Attend 2-3 monthly review clinics with respiratory physiology
- Inform re: research opportunities eg ADRT, Power of Attorney, decision not to progress with gastrostomy or Non Invasive Ventilation. Use of prognostic indicators and GSF ‘surprise’ question

**End of life support in the place of choice.**

- Transfer to palliative care services
- Joint decision re: End of Life options eg ADRT, Power of Attorney, decision not to progress with gastrostomy or Non Invasive Ventilation.

**Northwest Long Term Ventilation Service/ cough augmentation clinic**

- Screen for Continuing Health Care
- Inform GP and agree shared care protocol for Riluzole
- Symptom and co-morbidity management. Vaccinations
- Evidence of development of respiratory failure/ weak cough

**Regular review**

- Regular review
- Referral for gastrostomy – at the Long Term Ventilation Service or Salford Care Organisation as appropriate
- Refer to local community multi-disciplinary team inc therapy (Physio, OT, SALT, DT and psychology) and nursing teams
- Refer to orthotics for splints or braces
- Refer for environmental controls
- Refer for Augmentative and Alternative Communication
- Refer to wheelchair services
- Social services assessment for care support equipment and adaptations, support for carers and advice re: access to welfare benefits

**Support referral to MND Association**

- Early intervention palliative care at the point of diagnosis. Discussions re: future planning
- Dynamic palliative care input based on need. Provide emotional support for the person living with MND and carers, particularly at key moments when the condition changes.

**The North West End of Life Care Model : May 2015**