The Greater Manchester Motor Neurone Disease Care Model

**MND CARE CENTRE**

- 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
- 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
- Joint decision re: End of Life options eg ADRT, Power of Attorney, decision not to progress with gastrostomy or Non Invasive Ventilation. Use of prognostic indicators and GSF ‘surprise’ question
- Emergency review
- Evidence of development of respiratory failure/ weak cough
- Referral for gastrostomy – at the Long Term Ventilation Service or Salford Care Organisation as appropriate
- Joint respiratory clinic
- Northwest Long Term Ventilation Service/ cough augmentation clinic
- Screen for Continuing Health Care
- Cognitive changes – refer to Cerebral Function Unit or dementia services
- Referral for gastrostomy – at the Long Term Ventilation Service or Salford Care Organisation as appropriate
- Joint decision re: End of Life options eg ADRT, Power of Attorney, decision not to progress with gastrostomy or Non Invasive Ventilation. Use of prognostic indicators and GSF ‘surprise’ question
- 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.
- Equipment return when appropriate for family

**Diagnostic Pathway**

- Symptoms suggestive of MND
- MND diagnosed by another consultant or as an inpatient
- Referral for environmental controls
- Referral for Augmentative and Alternative Communication
- Referral for wheelchair services
- Refer to local community multi-disciplinary team inc therapy (Physio, OT, SALT, DT and psychology) and nursing teams
- Social services assessment for care support equipment and adaptations, support for carers and advice re: access to welfare benefits
- Support referral to MND Association

**Support re: future planning**

- 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.
- Continuing discussions re: decisions at all stages

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

**Bereavement support**

- Immediate support for family and carers.
- Phone call from MND care centre with family
- Christmas tree celebration

**Equipment return**

- Phone call from MND care centre with family

**Northwest Long Term Ventilation Service**

- Phone call from MND care centre with family
- Christmas tree celebration

**Support referral to MND Association**

- Phone call from MND care centre with family
- Christmas tree celebration

**Ongoing support available from the MND Association**

- Phone call from MND care centre with family
- Christmas tree celebration

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

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