The Greater Manchester Motor Neurone Disease Care Model

Symptoms suggestive of MND

MND diagnosed by another consultant or as an inpatient

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

Counselling/ emotional support/carer support

Consider alternative means to review if the patient is not able to travel to clinic eg remote clinics, out-reach clinics

Phone call from MND care centre with family

Christmas tree celebration

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

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

Transfer to palliative care services

End of life support in the place of choice.

Immediate support for family and carers.

Bereavement support

Inform GP and agree shared care protocol for Riluzole
Symptom and co-morbidity management.
Vaccinations

Referral for gastrostomy – at the Long Term Ventilation Service or Salford Care Organisation as appropriate

Evidence of development of respiratory failure/ weak cough

Joint respiratory clinic

Northwest Long Term Ventilation Service/ cough augmentation clinic

Refer to local community multi-disciplinary team inc therapy (Physio, OT, SALT, DT and psycholgy) and nursing teams

Regular review

Screen for Continuing Health Care

Refer to wheel chair services

Refer to orthotics for splints or braces

Refer for environmental controls

Refer for Augmentative and Alternative Communication

Social services assessment for care support equipment and adaptations, support for carers and advice re: access to welfare benefits

Equipment return when appropriate for family

Support referral to MND Association

Ongoing support available from the 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.

Continuing discussions re: decisions at all stages

- MND Care Centre
- Palliative Care services
- GP services
- Community Rehab Services
- Social Services
- NW long term Ventilation Service
- Endoscopy Services
- Specialist Services

The North West End of Life Care Model : May 2015

Advancing disease ↔ Increasing decline ↔ Last Days of life | First days after death ↔ Bereavement ↔

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