Norfolk MND Care and Research Network
Management of Motor Neurone Disease care pathway

Diagnosis of MND or probable MND

- Diagnosing Neurologist to refer to MND Network via MND Care & Research Network Coordinator (ext 7221)
- Coordinator to arrange follow up in MND clinic at NNUH/Cromer/Beccles/QEH as appropriate
- Coordinator to make telephone contact with patient within 2 weeks of referral
- Diagnosing Neurologist to signpost to MND Association for immediate support

At first MND clinic appointment

- Introductions to core team- Neurologist/Palliative Care Consultant/MND Coordinator/MNDA representative
- Further discussion of diagnosis as necessary
- Offer MNDA personal guide ‘Living with MND’ and also Norfolk MND Care & Research Network leaflet
- Consider riluzole as per shared care agreement and arrange baseline bloods
- Refer for initial baseline assessment by respiratory team (respiratory care then led by respiratory team in accordance with NICE, 2016 guidance)
- Refer to community neurology nursing team
- Refer for therapy input as needed (see box below)
- Request GP adds patient to local palliative care register where available
- Discuss driving and advise notification to DVLA
- Ensure patient aware of entitlements and direct to www.mndassociation.org/benefits advice. Consider DS1500

Review in MND clinic at intervals according to need

- Ongoing assessment of need and consideration of referrals to:
  - Nutrition clinic (refer to MND Gastrostomy Pathway)
  - Occupational Therapy/Physiotherapy
  - Respiratory MND Physiotherapist
  - Orthotics
  - Environmental controls
  - Wheelchair services
  - Speech & Language Therapy
  - Dietetics
  - Community specialist palliative care support
- Ensure patient is offered opportunity to discuss advance care wishes
- Consider follow up in supportive care and symptom management clinic (under Dr Barry)

For patients admitted to hospital

- Coordinator/member of neurology nursing team to visit patient whenever possible
- Ensure palliative care team aware of admission
- Review patients advanced care wishes/preferred place of care
- Ensure carers’ policy adhered to and carers are offered to stay with patient, whenever possible
- Coordinator to ensure community neurology team aware of admission