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
Ensure patient aware of local MNDA branch and support groups/volunteer support. Gain consent for referral
Discuss patient's/carer's research interest and discuss relevant studies
Obtain consent to share patient information with other health and social care professionals involved in person's care

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