Ipswich and East Suffolk MND Clinic

MND management pathway

*Diagnosing neurologist to request MND Coordinator Kate Barber join them for diagnosis clinic appointment whenever possible

Diagnosis of MND or probable MND

Diagnosing neurologist to refer to MND clinic under care of Dr Galton
Neurologist to notify MND coordinator Kate Barber of diagnosis
Coordinator to make telephone contact with patient within 2 weeks of referral
Neurologist to signpost to MND Association for immediate support/information
MND coordinator Kate Barber to gain consent for referral to MND Association

At first MND clinic appointment

Introductions to core team – Neurologist/MND coordinator/MNDA representative/Speech and Language Therapist/Respiratory Consultant
Further discussion of diagnosis as necessary
Offer MNDA personal guide '*Living with MND'* and also Ipswich clinic 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)
Request GP adds patient to Gold Standards Framework (GSF)
Discuss driving and advise notification of DVLA
Offer follow up
Ensure patient is aware of local MNDA FRG and support groups/volunteer support
Discuss patient's/carer's research interest and discuss relevant studies – (Consent for MND register)
Obtain consent to share patient information with other health and social care professionals involved in person's care

Review in MND clinic and 3 monthly intervals (minimum) or according to need

Ongoing assessment of need and consideration of referrals to:

- Occupational therapy/physiotherapy
- Orthotics
- Environmental controls
- Wheelchair services
- Speech and language therapy
- Dietetics
- Community specialist palliative care support/hospice

Ensure patient is offered opportunity to discuss advance care wishes

For patients admitted to hospital

Coordinator 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 relevant members of the MDT aware of admission