Motor Neurone Disease (MND) Guideline Recommendations

NHS
Greater Manchester
Neurorehabilitation & Integrated
Stroke Delivery Network

Definition: MND is a neurodegenerative condition that affects the brain and spinal cord, characterised by degeneration of primarily motor neurones. Presentation may include muscle weakness, wasting, cramps and stiffness of arms and/or legs; problems with speech and/or swallowing or, more rarely, breathing problems. The most common type of MND is amyotrophic lateral sclerosis. There are rarer forms of MND such as progressive muscular atrophy or primary lateral sclerosis, which may have a slower rate of progression.

Information & Support:

- Following diagnosis, ensure people are provided with a single point of contact for the specialist MND MDT, and provided with information about MND; (oral and written) and shared with family/carers if the person consents.
- Consider requirements for disclosure, such as notifying the Driver and Vehicle Licensing Agency (DVLA).
- Provide details of the MND Association.

Review Assessment:

- People with MND will need repeated, ongoing assessments, as their symptoms can worsen quickly. Priority should be given to ensuring continuity of care and avoiding untimely case closure.

Cognition:

- Explore any cognitive or behavioural changes with the person and their family members and/or carers as appropriate.
- Consider a formal cognition assessment, taking into account their communication ability, cognitive status and mental capacity e.g. Edinburgh Cognitive and Behavioural ALS Screen (ECAS).

Mobility & Activities of Daily Living (ADL's):

- Assess and anticipate any changes in a person's ADL's, including support with remaining in work. Provide equipment, splints and adaptations as appropriate without delay. Consider completing the Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS).
- Consider prompt referral to specialist services such as assistive technology, orthotics and wheelchair services. People should be assessed, and equipment provided without delay.
- Consider seeking funding support from MND Association for specialist equipment such as seating.
- Consider an exercise programme to: maintain range of movement, prevent contractures, reduce stiffness and optimise function and quality of life. Ensure family/carers are able to help with exercise programmes and provide advice on safe manual handling

Nutrition & Swallowing:

- At diagnosis and at multidisciplinary team assessments, check the following: weight & any changes – calculate % weight loss, swallowing function, changes in nutrition and fluid intake, ability to eat and drink and prepare food and drinks.
- Check for potential causes of reduced intake – swallowing difficulties, reduced appetite, gastrointestinal symptoms, limb weakness, low mood or depression
- When eating and drinking/preparation of food and drinks is an issue consider the need for eating and drinking aids and altered utensils to help them take food from the plate to their mouth, the need for help with food and drink preparation, advice and aids for positioning, seating and posture while eating and drinking, dealing with social situations (for example, eating out)
- For swallowing problems arrange for a swallowing assessment, manage factors contributing to swallowing problems such a modifying food and drink, respiratory symptoms, risk of aspiration and fear of choking. Ensure advice sought for aids, positioning, seating and posture, dealing with social situations e.g. eating out
- If the person has problems with saliva (sialorrhoea), assess the volume and viscosity of the saliva and the person's respiratory function, swallowing, diet, posture and oral care.
- Discuss gastrostomy at an early stage, and at regular intervals as MND progresses, explaining the benefits of early placement and risk of late placement, be aware some people will not want to have a gastrostomy. Gastrostomy referrals should take place without unnecessary delay by contacting the MND Care Centre
- For patients with frontotemporal lobe dementia who lack mental capacity, particular attention should be paid to nutritional and hydration needs. NICE provides specific guidance on management of gastrostomy discussions with these patients.

Communication:

- Assess and provide support if people develop communication difficulties. Consider provision of AAC equipment without delay if required. Provide with information and support for Voice Banking and Message Banking without delay.
- Liaise or refer the person to a specialised NHS AAC hub if complex high technology AAC equipment (for example, eye gaze access) is needed or is likely to be needed e.g. ACE Centre for Greater Manchester.
- Involve other healthcare professionals, such as occupational therapists, to ensure that AAC equipment is integrated with other assistive technologies, such as environmental control systems and personal computers or tablets.
- Provide ongoing support and training for the person with MND, and their family members and/or carers in using AAC equipment and other communication strategies.

Respiratory Function:

- Monitor respiratory status on a regular basis e.g. frequency of lower respiratory tract infections, aspiration risks, saliva management, signs of hypercapnia etc.
- Teach unassisted breath stacking and/or cough augmentation techniques such as manual assisted cough for people who have an ineffective cough
- Assess cough peak flow rate if able (If <270L refer to the North West Ventilation Service (NWVS) for cough augmentation assessment)
- Refer on to the NWVS for consideration of long term NIV/invasive ventilation if clinically indicated

Palliative Care & Psychological Support:

- Consider referral to a specialist palliative care team for people with current or anticipated significant or complex needs, for example, psychological or social distress, troublesome or rapidly progressing symptoms and complex future care planning needs.
- Consider referring people at any stage of MND to palliative care services to discuss advanced decisions and care at end of life.

The content of this poster was derived from the NICE Guidelines for 'Motor Neuron Disease: Assessment and Management' (NICE, 2016) and formulated by Samantha Ikin (Technical Instructor), Jennifer Malone (Physiotherapist) and the MND Care Centre on behalf of the Greater Manchester Neurorehabilitation & Integrated Stroke Delivery Network (hosted by Salford Royal)

Unique Identifier: NOE44(21), Review Date: October 2023.