PHYSIOTHERAPY GUIDELINES FOR MOTOR NEURONE DISEASE

Prepared by: Physiotherapy Rehabilitation Clinical Interest Groups

Applicability: Management of Motor Neurone Disease by Physiotherapists

Evidence Base

These guidelines have been developed with reference to the Motor Neurone Disease Resource File (2007), The National Service Framework for Long-term Conditions (2005), NICE Guidance Motor neurone disease – The use of non-invasive ventilation in the management of motor neurone disease (2010) and a consensus of best practice by the Southern and Eastern Physiotherapy Rehabilitation Clinical Interest Groups. The draft guidelines were also commented upon by representatives of the Motor Neurone Disease Association and the Motor Neurone Disease Peninsular Network.

General Principles

1.1 Care of people who have motor neurone disease should be provided as a team effort with good communication with all other disciplines and agencies involved.

1.2 Physiotherapy intervention should be provided by clinicians with experience of managing motor neurone disease, who can provide continuity of service. Where possible the named Physiotherapist should hold a static position. Clinicians should have access to other qualified staff that can support them if necessary. The Motor Neurone Disease Peninsular Network is a resource that is available for further advice and information.

1.3 Flexibility and priority of response to ensure speed in service delivery.

1.4 Patients should be offered regular monitoring and review.

1.5 The Physiotherapist's role is to:-

- aim to maintain optimum function and physical ability
- aim to maintain mobility with active and passive exercise and provision of appropriate walking aids
- aim to prevent contractures through range of movement and stretching exercises, provision of splints and management of tone.
- advise carers on posture, safe moving and handling techniques
- assess lung function and teach breathing exercises and techniques to maximise expansion and ability to cough and clear secretions
- teach relaxation techniques

2. Assessment

Version Control: MND Physiotherapy Guidelines 2011 VS 1
2.1 People with a diagnosis of motor neurone disease, who are referred for Physiotherapy, should be assessed as a priority, regardless of the setting.

2.2 Assessment (either individual or multidisciplinary) needs to show evidence of:-

2.2.1 Subjective assessment:

- Course of the disease
- Social history and support network
- Lifestyle
- Expectations

2.2.2 Objective assessment:

- Level of consciousness and orientation
- Basic ability to communicate
- Motor ability
- Co-ordination
- Respiratory system*
- Swallow function
- Equipment and environment
- Bladder and bowel function
- Mood
- Pain

*NICE (2010) guidance states: ‘A healthcare professional from the multidisciplinary team who has appropriate competencies should perform respiratory function tests at the following times (or arrange them to be performed):

- As part of the initial assessment to diagnose MND, or soon after diagnosis (to establish baseline function).
- Every 3 months, but possibly more or less often depending on:
  - whether there are any symptoms and signs of respiratory impairment (see table below)
  - rate and progression of MND
  - the patient’s preference and circumstances’

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Signs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breathlessness</td>
<td>Increased respiratory rate</td>
</tr>
<tr>
<td>Orthopnoea</td>
<td>Shallow breathing</td>
</tr>
<tr>
<td>Recurrent chest infections</td>
<td>Weak cough</td>
</tr>
<tr>
<td>Disturbed sleep</td>
<td>Weak sniff</td>
</tr>
<tr>
<td>Non-refreshing sleep</td>
<td>Abdominal paradox (inward movement of the</td>
</tr>
<tr>
<td>Nightmares</td>
<td>abdomen during inspiration)</td>
</tr>
<tr>
<td>Daytime sleepiness</td>
<td>Use of accessory muscles of respiration</td>
</tr>
<tr>
<td>Poor concentration and/or memory</td>
<td>Reduced chest expansion on maximal</td>
</tr>
<tr>
<td>Confusion</td>
<td>inspiration</td>
</tr>
<tr>
<td>Hallucinations</td>
<td></td>
</tr>
<tr>
<td>Morning headaches</td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td></td>
</tr>
<tr>
<td>Poor appetite</td>
<td></td>
</tr>
</tbody>
</table>

Table 1: Signs and symptoms of respiratory impairment

The process of assessment might highlight the need to involve other members of the multidisciplinary team e.g. nursing, occupational therapy, speech and language therapy and respiratory medicine.

3. **Goal Setting**

Version Control: MND Physiotherapy Guidelines 2011 VS 1
3.1 Goal setting should ideally occur as part of a team effort, and should involve the person and carer.

3.2 Goals should be focused at the level of activity and/or participation.

3.3 Goals should be timed and should make reference to long and short term aims.

4. **Treatment/Management**

4.1 The natural course of motor neurone disease (MND) can be described as consisting of several stages. These are not clear-cut, but represent a continuum through which the speed of progression will vary from patient to patient. The stage of the disorder can be used as a rough guide to assist Physiotherapists to plan treatment programmes in conjunction with thorough assessment of the individual problems and needs of the patient. There is some evidence that exercise is beneficial in maintaining function.

The overall goals of intervention will vary as the condition progresses.

- Early stage - to optimise remaining function
- Middle stage - to maintain functional mobility
- Late stage - to maximise quality of life

Some aims will remain constant throughout intervention:-

- provision of information to patients and carers
- provision of psychological support

4.1 **Early stage**

The patient can mobilise and manage activities of daily living independently. There may be weakness of specific muscle groups that limits performance of tasks and/or endurance. Foot drop may be apparent on one or both sides and weakness of intrinsic muscles in one or both hands may interfere with fine motor activities.

Physiotherapy may include: -

- preserving optimum level of mobility
- active range of movement exercises
- strengthening exercises
- aerobic activities
- training in pacing activity/fatigue management
- stretching of affected joints
- teaching breathing exercises
- provision of appropriate equipment and assistive devices to support weak muscles.
- provision of appropriate walking aids
• patient and carers instructed in performing active assisted and/or passive range of motion exercises at affected joints to prevent contractures

In the early stages exercises should be functional where possible and performed at an intensity to avoid extreme fatigue.

4.3 **Middle stage**

The patient may remain ambulatory but have severe weakness in certain muscle groups. Severe foot drop is likely and there may be marked weakness in one or both hands. The patient may need assistance to rise from a chair and there will be mild to moderate limitation of function. A wheelchair may be required for part of the day.

Physiotherapy may include:-

• provision of adaptive equipment (e.g. Ankle Foot Orthosis, splints, arm slings/trays, riser-recliner chairs) and wheelchair. Consider application to MNDA for rapid access to equipment, however local Equipment Services should be accessed initially

• provision of walking aids (Advice on footwear)

• management of oedematous limbs. Referral/discussion with GP to identify the appropriate management route

• soft collar provision

• active, assisted active, passive and/or aerobic exercise, as appropriate

• teaching breathing exercises and assisted coughing

• advice regarding pressure care and provision of pressure relieving seating/mattress

• management of spasticity. prevention of contractures

• position for comfort

4.4 **Late stage**

This stage is characterised by progressive weakness and deterioration in mobility, dexterity and endurance. The patient uses a wheelchair when out of bed or remains in bed and it is probable that a hoist is required for transfers. Pain can be a major problem.

Physiotherapy may include:-

• teaching carers to perform gentle passive stretches, heat treatment and/or massage to relieve pain and improve comfort

• advising carers regarding positioning and movement of the patient in bed

• advising and teaching carers regarding manual handling issues

• modified postural drainage to decrease retention of secretions, self-assisted or carer-assisted coughing and airway clearance techniques may need to be taught. A suction machine maybe required at this stage. Carers may be shown how to use suction to keep the patient's mouth clear of secretions but only experienced health professionals should attempt deep suction, when appropriate in the community setting.
5 **Outcome Measurement**

5.1 There is recognition that while objective measure may be useful during assessment, repeated measuring is probably not appropriate for this client group. Objective measures that may be useful include:

- Modified fatigue impact scale
- Berg balance scale
- Elderly Mobility Score
- Timed walk
- Timed Unsupported Steady Stand
- Ashworth scale

5.2 Goal attainment scaling is probably the most suitable outcome measure in the later stages of the disease.

6. **Information and Education**

6.1 People who have motor neurone disease should have access to information regarding their condition. A comprehensive range of literature is available from:

- **Motor Neurone Disease Peninsular Network.** Telephone: 07917 050428
  Email: lou.jarrett@plymouth.nhs.uk
- **Motor Neurone Disease Association.** Telephone: 01752 695 273
  www.mndassociation.org
- **MND Connect.** Telephone: 08457 626262

6.2 Where exercises or activities are given, this should be support written information.

6.3 People should be provided with contact information for relevant groups e.g. MNDA.

6.4 People should be supplied with the name and contact number of their Physiotherapist, and with other agencies referred to, where appropriate.

7. **Transfer of care, discharge planning and discharge**

7.1 People with a diagnosis of MND should not be discharged from the Physiotherapy Service.

7.2 Frequency of physiotherapy input can be determined on an individual basis. If a person with MND is not given a set follow-up appointment, they should be given a contact number and be able to re-access the service at will.

When care is transferred from one Physiotherapist to another, written information should accompany the transfer.
References:

