

# SCOTTISH MUSCLE NETWORK

## Generic Neuromuscular Pathway

#### NOTE

This guideline is not intended to be construed or to serve as a standard of care. Standards of care are determined based on all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve. Adherence to guideline recommendations will not ensure a successful outcome in every case, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results. The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This judgement should only be arrived at following discussion of the options with the patient, covering the diagnostic and treatment choices available. It is advised, however, that significant departures from the national guideline or any local guidelines derived from it should be fully documented in the patient's case notes at the time the relevant decision is taken.

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#### **Neuromuscular websites**

There are many websites with information on neuromuscular disorders and these are just a few resources below:

- Information on specific conditions can be obtained from the Scottish Muscle Network Website
- Muscular Dystrophy UK
- Neuromuscular Disease Centre
- Pod NMD Physiotherapy- A resource for neuromuscular physiotherapists
- DMD Care UK
- Info on current trials in DMD
- Info on Charcot-Marie-Tooth (CMT) UK

### **Assessment and Management**

Assessment		Management
Muscle Strength	It may be helpful to chart muscle strength if patient is trying specific medication that could impact on strength. Look at all muscle groups as even in certain conditions such as Fascioscapulo-humeral muscular dystrophy weakness in the lower limbs is evident. A modified MRC scale can be used. Scales such as the North Star Ambulatory Scale (NSAA) or the North Star Scale for Dystrophinopathies (NSAD) are useful to look at areas such as function and power.	General Exercise for long term maintenance Targeted Exercise for short term solutions Fatigue Management Coaching Daily Stretching Practice Passive and passive assisted movement either land or water-based.
Range of Movement	Hypermobility Contractures Muscle weakness Trismus	Orthoses Stretches Exercise
Functional assessment	School, Home, Work Check transfers, assess challenges the patient faces during day- to-day activities and assess their risk on joints, falls and pain.	Develop strategies to undertake activities differently, fatigue management, pain management. O.T. assessment

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Assessment		Management
Balance and Falls	Check trunk rotation Berg balance scale Peripheral sensation Sensory motor exercises Check, eyes, ears, strength and sensation as these areas are all important for balance	Orthoses, Footwear, Walking aids, Exercise Stretches, trunk stability, develop a falls strategy www.smn.scot.nhs.uk
Postural Assessment	Assess all postures Sleep Sitting (Work, Wheelchair, Home) And Standing	Advise on movement strategies i.e. the need to avoid static postures <a href="https://www.smn.scot.nhs.uk">www.smn.scot.nhs.uk</a>
Fatigue assessment	Discuss fatigue profile in relation to sleep quality, static and dynamic movement. When is fatigue worse, does a particular activity increase fatigue etc?	Explore fatigue strategies such as pacing, work / leisure balance, exercise and activity and rest. www.smn.scot.nhs.uk
Pain Assessment	Assess pain whether it is neurogenic or nocigenic (or a combination) and discuss pain management appropriately.	Pain Team, TeNS, The balance between activity and rest, Orthoses, Medication, Postural management, Fatigue management.  www.smn.scot.nhs.uk
Respiratory Assessment	Assess frequency of chest infections, secretion mobilisation, cough effectiveness, breathlessness at rest / activity	Respiratory Physiotherapy - a specialist assessment may be required. Cough strategies, lung volume recruitment, secretion mobilisation strategies
Mobility Assessment	Assess Walking aids, Orthotics, Footwear, Balance, Falls. Risk assessment for wheelchair provision	Wheelchair provision for part, whole of day. OT assessment, transfers.
Spinal Assessment	Assess spinal symmetry, posture in sitting and standing and chest shape. Assess pain profile (frequency, intensity, and duration) if appropriate. Assess functional ADL and sleep profile where required.	Referral for spinal assessment, orthotics, stretches and exercise, pain management, fatigue management and postural management may be indicated.

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