# DUCHENNE MUSCULAR DYSTROPHY SCOTTISH PHYSIOTHERAPY MANAGEMENT PROFILE

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# INTRODUCTION

**Background:** Duchenne Muscular Dystrophy (DMD) is often described in the literature as a relentlessly progressive muscle wasting disorder that affects mainly boys. It affects 3:10000 live male births across the world and without intervention, young men will rarely live beyond 19 years. There are some instances where females may show similar symptoms and disease progression but are affected to a lesser degree. These females are known as manifesting carriers.

In recent years medical advances have not only progressed in the area of diagnosis but also in treatment and management. Life expectancy has improved and many can expect to live into their 20's and 30's. In some countries such as Denmark and Holland, where management of this condition has been treated as a specialist area for many years, reaching the forties is not unusual. It is also felt that the way in which social care is delivered in these countries is a contributing factor to this increase in life expectancy.

**Needs analysis:** This booklet has been written to assist physiotherapists, to offer effective intervention at the different stages of Duchenne Muscular Dystrophy. Many physiotherapists have expressed a desire for a care pathway or indeed a clinical guideline, as keeping abreast of the changes in management and policy can be difficult. This is particularly relevant where a therapist is newly qualified or has a generic caseload with many different conditions to take account of. This booklet aims to highlight current practice in this field and direct the reader to useful resources where appropriate.

**Methodology:** This booklet has been written with the collaboration of experienced therapists from around Scotland and is intended for the Scottish physiotherapy service. It reflects current care offered and delivered in Scotland. An extensive literature review was undertaken and in the absence of a very strong or strong evidence base (relating to levels 1 and 2 of Sackett's levels of evidence), expert opinion has been sought using group consensus from experts in the field.

**Aim**

- This aim of this booklet is to assist healthcare professionals make clinical judgements and provide information to help with the decision making process. Appendices one to six will offer assessment protocols and an explanation of current practice.
- This booklet is due to be reviewed in November 2012. Please ensure that you are using the most up to date booklet.

**Conclusion**: Your views on this booklet would be gratefully appreciated. If you have any queries regarding any of the material contained in this booklet, please contact:

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If you have a specific query and wish to talk to a physiotherapist in your area, please refer to the contact details in appendix nine

| STAGE I – PRE – DIAGNOSIS / EARLY STAGE | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **Description** | **Assessment** | **Physiotherapy Intervention** | **Respiratory Intervention** | **Orthopaedic Intervention** | **Orthotic Management** | **Equipment Provision** | **Specialist Services** | **Education** |
| Speech / Cognitive Delay<br><br>Toe walking<br><br>Waddling gait / gait abnormalities<br><br>Developmental delay<br><br>Tight gastrocnemius complex<br><br>Enlarged calf circumference<br><br>Gower's manoeuvre – Boys will rise from the floor via a prone position using their hands to "walk" up their body.<br><br>Muscle weakness (particularly proximal) | Generic physiotherapy assessment (Prior to a definitive diagnosis the physiotherapist should use a general assessment and may continue with this in the early stages if the child is unable to follow a more specialised assessment). | Referral to Paediatric Neurologist and/or Community Paediatrician Always copy G.P into referrals<br><br>Encourage activities as able (appendix 8)<br><br>Avoid eccentric exercise (In conditions where there is instability of the muscle cell membrane, it is advisable to avoid strengthening exercises and eccentric muscle work as this can cause further damage to the muscle cell).<br><br>Introduce and advise on stretches for tight muscle groups and joints (appendix 8) | Not usually required at this stage | Not usually required at this stage | For foot variations such as pes cavus or flat feet it may be useful to refer to an orthotist for insoles / inlays<br><br>Night splints may be appropriate if loss of range of dorsiflexion is noted (appendix 8) | Not usually required at this stage | Refer to Care Advisor from the Muscular Dystrophy Campaign (appendix 9)<br><br>Parents may find a copy of the DMD care card (patient information document) helpful at this stage. This can be downloaded from the Scottish Muscle Network website (appendix 9)<br><br>Family counselling may be required at any stage of this condition | Advice for P.E. teachers on fatigue issues and muscle weakness (appendix 8)<br><br>Classroom assistant may be required<br><br>Taxi to/from school may be helpful |

| STAGE II – YOUNG MOBILE | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **Description** | **Assessment** | **Physiotherapy Intervention** | **Respiratory Intervention** | **Orthopaedic Intervention** | **Orthotic Management** | **Equipment Provision** | **Specialist Services** | **Education** |
| Progressive muscle weakness<br>Pseudo-hypertrophy of muscle e.g. gastrocnemius / deltoid.<br>Risk of contractures and tightness at end of range particularly ankles, hips and wrist flexors<br>Difficulty with jump / run / hop and frequent falls.<br>Difficulty with stairs and rising from chairs.<br>Increased lumbar lordosis and trendelenberg style gait.<br>Muscle cramps and pain after activity. This can be particularly troublesome in bed at night | North Star Ambulatory Assessment (modified version for centres not signed up to data collection appendix 2)<br><br>Assess every 6-12 months | Liaise with specialist neuromuscular physiotherapist if there is one in your area<br><br>Encourage activities e.g. swimming as able<br><br>Avoid muscle fatigue<br><br>Avoid strengthening /resisted exercise especially eccentric muscle work<br><br>Continuation of stretches appropriate to stage of progression (refer to MDC booklet on physiotherapy)<br><br>Liaise with Lead Consultant re. steroid therapy (appendix 1) | Encourage cardiovascular fitness<br><br>Baseline lung function tests | Not usually required at this stage | Night orthoses for gastrocnemius complex when ankle range of movement is compromised<br><br>Continuation with inlays / insoles if appropriate | Aim to get out of buggy by age five years and in to a suitable lightweight manual wheelchair if required for longer distances.<br>If fatigue / falling is problematic a lightweight chair may also be necessary at this stage - refer to MDC wheelchair and seating guidelines (appendix 9)<br><br>Specialised seating and equipment in school may be beneficial -refer to MDC booklet on inclusive education (appendix 9) | Provide the family with contacts for support / advice and information on DMD (appendix 9)<br>Genetic counselling<br>If on steroid therapy it is important that boys are referred for dietary advice)<br>Pain management<br>Cardiology<br>Dietetics<br>Care Adviser<br>Social services<br>O.T. (Housing and adaptations)<br>Clinical Psychologist<br>Sleep Scotland if problems with sleeping through the night (appendix 9) | Raise awareness of future challenges re. access to curriculum and accessibility of classrooms and facilities<br><br>Additional support for learning strategies may be required – refer to Action Duchenne Learning and behaviour toolkit for DMD booklet which can be downloaded from their web site (appendix 9) |

| STAGE III – GOING OFF FEET | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **Description** | **Assessment** | **Physiotherapy Intervention** | **Respiratory Intervention** | **Orthopaedic Intervention** | **Orthotic Management** | **Equipment Provision** | **Specialist Services** | **Education** |
| Poor core stability<br><br>Increased effort and time to rise from chair / floor<br><br>Increasing frequency of falls<br><br>Requires a wide base of support<br><br>Difficulty standing with heels down<br><br>Difficulty standing still for >3s<br><br>Tires easily with physical activity<br><br>Increased upper limb weakness<br><br>Asymmetry noted in standing and sitting | North Star Ambulatory Assessment (NSAA) Appendix 2<br><br>Moving and handling risk assessment as per local policy (both at home and school) | Continuation of stretches / passive movements and exercises as able<br><br>Hydrotherapy<br><br>Standing frame as able (no consensus as to how long or how often – individual assessment as necessary. Be aware of children who complain of back pain especially with increased lumbar lordosis, as vertebral fractures are not uncommon in boys with DMD).<br><br>Heel wedges may be appropriate to assist standing if dorsiflexion is compromised. | Games to promote effective in – expiration<br><br>Wind instruments<br><br>Blowing bubbles<br><br>Incentive spirometer to promote good expiratory technique<br><br>Inspiratory muscle training not recommended due to the fact it requires resistance training<br><br>Monitor spirometry (appendix 4) | Spinal monitoring - refer to Scottish National Paediatric Spine Deformity Service (RHSC, Sciennes Road, Edinburgh EH9 1LF) if asymmetry noted or young person starts to use wheelchair on a daily basis.<br><br>Continue to monitor lower limb contractures | Walking AFO's not usually recommended as this can cause a deterioration in balance<br><br>Continue with night AFO's if child is compliant and AFO's recommended when sitting in wheelchair for long periods of time (appendix 8) | Manual wheelchair with supportive cushion and backrest. Referral for powered tilt in space wheelchair. It may be appropriate to consider a powered chair with advanced functions (see MDC booklet on wheelchairs and seating). Alternative funding may be required. In this instance, please liase with Marina Di Marco (appendix 9) if child resides within the West of Scotland.<br><br>Familiarisation with hoisting techniques<br><br>Profile bed | Motability (adapted vehicle should be considered at this stage). Ensure young person always uses a headrest for transport (refer to MDC booklet on wheelchair provision and special seating)<br><br>Introduction of cardiac monitoring recommended at this stage | Moving and handling<br><br>Postural support within the classroom and increased assistance may be required for toileting |

| STAGE IV – EARLY POWER CHAIR USER | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **Description** | **Assessment** | **Physiotherapy Intervention** | **Respiratory Intervention** | **Orthopaedic Intervention** | **Orthotic Management** | **Equipment Provision** | **Specialist Services** | **Education** |
| Increased risk of scoliosis<br><br>No static standing balance<br><br>Sitting balance compromised<br><br>Some ability to assist in standing transfers<br><br>Some ability to self propel manual wheelchair but be aware of fatigue issues and repetitive strain<br><br>Difficulty raising arms above head | NSAA (appendix 2)<br><br>E.K. Scale (appendix 3) | Continue monitoring upper limb function<br><br>24 hour postural management (appendix 8)<br><br>Active assisted exercise / passive movements and stretches<br><br>Particular attention to wheelchair and moving and handling both pre and post spinal fusion (appendix 7) | Chest clearance techniques (appendix 6) Introduce lung volume recruitment techniques i.e. breath stacking and ambu bag techniques<br><br>Assisted cough<br><br>Teach parents / carers chest clearing techniques (Better introduced when patient does not have a chest infection) | Regular review<br><br>Tenotomies may improve sitting posture if ankle deformity is problematic.<br><br>Surgical tendoachilles lengthening procedures are generally percutaneous and in most cases require a general anaesthetic. This is usually followed by two weeks in plaster. Bilateral ankle foot orthoses after removal of plasters are required.<br><br>Spinal surgery may be appropriate at this stage. | AFO's recommended when sitting in wheelchair<br><br>Consideration to spinal orthoses for function and comfort particularly if person is not a suitable candidate for spinal surgery (if scoliosis is pronounced or person is overweight then this may not be appropriate). | Introduction to sleep system if younfg person is unable to change position in bed<br><br>Standing frame should be discontinued if young person complains of pain and / or contractures at hip / knees are problematic.<br><br>Hoist (assess for appropriate sling with head support in collaboration with occupational therapist).<br><br>Height adjustable tables may be helpful | Dietician<br><br>Speech and language therapy assessment for chewing and swallowing may be indicated. Be aware of changes in eating pattern and monitor weight. Some children may feel that eating takes too long and fatigue issues emerge. Feeding ability may be compromised and child does not want to ask for help at school<br><br>Introduction of care agency to assist with areas of personal care<br><br>Respite services / befrienders | Secondary school access assessment<br><br>Educational psychologist / Family counselling may be useful at any stage<br><br>Coordinated support plan if appropriate |

| STAGE V – LONG TERM POWERED WHEELCHAIR USER | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **Description** | **Assessment** | **Physiotherapy Intervention** | **Respiratory Intervention** | **Orthopaedic Intervention** | **Orthotic Management** | **Equipment Provision** | **Specialist Services** | **Education** |
| Unable to assist with transfers<br><br>Deteriorating head control<br><br>Powered wheelchair for independent mobility<br><br>Increased risk of scoliosis if no spinal fusion<br><br>Less effective cough<br><br>Poor circulation to extremities<br><br>Oedematous ankles<br><br>Gastrostomy may be indicated<br><br>Fear of falling asleep | E.K. Scale<br><br>Epworth sleepiness scale (appendix 5)<br><br>Quality of Life | Passive movements and stretches<br>Postural management<br><br>Encourage regular changes in position perhaps with an advanced powered wheelchair (lie to stand functions).<br><br>Current recommendations are to recline for at least ten minutes every hour if appropriate to rest neck muscles in particular<br><br>Monitor pressure areas and skin folds particularly if not had a spinal fusion. Posterior aspect of ankle joints can also be problematic with regard to pressure | Non invasive ventilation<br><br>Glosopharyngeal breathing (appendix 5)<br>If appropriate<br><br>Teach lung volume recruitment techniques (appendix 6)<br><br>Sleep assessment may be required to monitor nocturnal blood gases (of particular importance during REM sleep)<br><br>Pulse oximetry | Monitoring of hip joints – some older boys complain of hip pain, particularly those with a scoliosis – be aware of hip subluxation | As previous stage | Wheelchair provision with adequate degree of tilt (refer to MDC booklet on wheelchairs and seating)<br><br>Ensure adequate head support particularly during feeding and travelling).<br><br>Environmental controls | Pain Team<br>Palliative team if not already known to patient<br>Transition support worker if available<br><br>Continence care adviser for those who find toileting difficult<br>Uribags (discreet bottles) are available on prescription from Fittleworth Tel:0800 783 7148)<br>Tissue viability nurse if pressure care is problematic<br><br>Young disabled school leavers teams or physical disability teams for onward referral. | Access issues for further education<br><br>Benefits such as ILA and Direct Payments if aged 16 years or over<br>Refer to welfare rights officer for up to date information on benefits. |

| STAGE VI – Palliative Phase | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **Description** | **Assessment** | **Physiotherapy Intervention** | **Respiratory Intervention** | **Orthopaedic Intervention** | **Orthotic Management** | **Equipment Provision** | **Specialist Services** | **Education** |
| Totally dependent for all care<br><br>Functional muscle power may be limited to finger movements<br><br>Difficulty chewing and swallowing / loss of appetite and weight loss<br><br>Frequent chest infections<br><br>Multiple contractures<br><br>Day time ventilatory assistance<br><br>Difficulty sitting upright in chair – spending long periods of time in bed<br><br>Pain | Pain and comfort<br><br>Respiratory effort<br><br>Circulation<br><br>Quality of life | Passive movements and regular positioning to relieve pain and pressure<br><br>Complementary therapies | Cough augmentation and chest clearing techniques if tolerated<br><br>Ventilation used more frequently at this stage.<br><br>Regular auscultation and monitoring | Not usually appropriate | Generally not tolerated at this stage<br><br>Positioning with pillows or sleep system for comfort<br><br>Occasionally collar is required | Specialised pressure reducing mattress may be required | Family counselling<br><br>Dietician (augmented feeding)<br><br>District nurse<br><br>Tissue viability nurse<br><br>Respite services<br><br>Hospice<br><br>Home support team | Home tuition if appropriate |

## Appendix One
## Steroid Therapy and DMD

In recent years, the prescription of steroid therapy has become the gold standard in the treatment and management of ambulant boys with DMD. The most commonly prescribed steroids are prednisolone and deflazacort. The steroid prescribed will depend upon the Consultant and the dosage prescribed is directly related to the young person's weight. Once steroid therapy has commenced the young person will be weighed regularly and specific health checks will be carried out to ensure the maintenance of an optimum dosage and to monitor for any side -effects

Steroid therapy is most effective if commenced when the child has reached their developmental potential usually between the ages of 3 and 6 years. Due to the immuno-supressant effect of steroids, the child should be up to date with all of their injections.

The exact way the steroids work is not yet fully understood however, it is felt that steroids have an effect on the inflammatory process within the muscles prevalent in DMD. Children who are treated with steroids have been shown to have an increase in muscle strength and functional ability. Some children are able to hop, run and ride bikes, tasks they would have been unable to perform without steroid therapy. The frequency of the steroid regime does vary and at the moment there is no clear consensus as to which regime should be used. Daily steroids have been shown to produce a more successful increase in muscle strength however, side effects are more likely. Young people who have pulsed steroid therapy i.e. 10 days on and 10 days off are felt to have time to recover on the days where steroids are not taken and in these cases, side effects may be less problematic. Ongoing research in this area is vital and throughout the U.K. and Europe, various trials are underway.

Children on steroids generally maintain ambulation longer than those who do not take steroids. In some cases walking can be carried on in to the mid teens. These children are also at less risk of scoliosis and some young people also display maintenance of their respiratory function rather than the gradual deterioration of lung function and breathing ability synonymous with the natural progression of this condition.

Side effects commonly associated with prolonged use of steroids are reduced bone mineral density with an increased risk of fractures (particularly vertebral fractures), weight gain and behavioural problems. Ongoing monitoring for children on steroid therapy is important and approximately 1/3$^{rd}$ of children are not suitable for this type of treatment.

Steroids are generally stopped when the young person becomes wheelchair dependent however continuation with steroids is now being undertaken in some centres for respiratory benefits. At the moment, it is not recommended that steroids are commenced when the young person is wheelchair dependent as coming off them can be associated with sudden respiratory failure. www.enmc.org

## Appendix Two
## North Star Assessment Protocol

This protocol has been developed via a lengthy process of review and consensus by the Physiotherapy Assessment and Evaluation Group of the North Star Clinical Network for Paediatric Neuromuscular Disease Management (NSCN). One of the key aims of this national, multidisciplinary project has been to standardise assessment techniques for ambulant children with DMD. Twenty specialist paediatric neuromuscular centres from across the UK have participated. The charity Muscular Dystrophy Campaign has substantially funded and supported the activity of the NSCN. For more information re the North Star project and assessment detail contact **northstar@muscular-dystrophy.org**

**North star ambulatory assessment (NSAA)**
**Steroids on day of assessment Y/N** **State which day of cycle**_____

| | North Star Ambulatory Assessment | Score 2,1,0 | Time (00.0s) | |
|---|---|---|---|---|
| 1 | Stand | | | |
| 2 | Walk (10m) | | | |
| 3 | Sit to stand from chair | | | |
| 4 | Stand on one leg - R | | | |
| 5 | Stand on one leg – L | | | |
| 6 | Climb step - R | | | |
| 7 | Climb step – L | | | |
| 8 | Descend step - R | | | |
| 9 | Descend step – L | | | |
| 10 | Gets to sitting | | | |
| 11 | Rise from floor | | | |
| 12 | Lifts head | | | |
| 13 | Stands on heels | | | |
| 14 | Jump | | | |
| 15 | Hop – R | | | |
| 16 | Hop - L | | | |
| 17 | Run | | | |
| | **TOTAL NSAA (out of 34)** | | | |

**Manual muscle testing:**

| Muscle Group | Grade (0-5) R | L | Comments |
|---|---|---|---|
| Neck Flexors | | | |
| Neck Extensors | | | |
| Shoulder Flex. | | | |
| Shoulder Exts | | | |
| Shoulder Abds | | | |
| Elbow Flexors | | | |
| Elbow Ext. | | | |
| Hip Flexors | | | |
| Hip Extensors | | | |
| Hip Abductors | | | |
| Hip Adductors | | | |
| Knee flexors | | | |
| Knee Extensors | | | |
| Dorsiflexors | | | |
| Planterflexors | | | |
| **Total score** | | | |
| **MRC%** | | | |

| FVC | Absolute value | %age pred for height | Comments |
|---|---|---|---|
| **Test 1** | | | |
| **Test 2** | | | |
| **Test3** | | | |

| *Joint range* | R | L | Comments |
|---|---|---|---|
| Elbow extension | | | |
| Hip extension | | | |
| Knee extension | | | |
| Ankle dorsiflexion | | | |
| ITB tightness | | | |
| | | | |
| | | | |
| | | | |
| | | | |

## **Management of joint range** (link to assessment of joint range)

| | |
|---|---|
| **Stretches** | summary of advice given & to who, include frequency and reps |
| **Orthotics** | e.g. FO's**,** AFO's, KAFO's |
| **Usage** | e.g. night splints + estimated wear time and compliance |
| **General advice given** | e.g. hydro/swimming |
| **Surgery** (If any –specify) | |
| **Comments** | e.g. any problems with any of the above, include compliance where possible |

## Equipment

| **Mobility Equipment** | |
|---|---|
| **Wheelchair/buggy** | Y/N |
| **Model** | |
| **Wheelchair cushion** | Y/N |
| **Model** | |
| **Wheelchair services** | |
| **Contact** | |
| **Comments** | |

**Gait analysis:** (brief description, include any aids used, frequency of falls)

**General activity levels:**
Include 'extra-curricular' activities such as swimming, cycling horse-riding

| **Parent/carer perception of general health & well being**<br>Improvement/deterioration/no change<br>Comments: |
|---|

| **Patient perception of general health & well being:**<br>Improvement/deterioration/no change<br>Comments: |
|---|

**Spinal Posture**

| **Sitting**<br>Draw, describe | **Standing**<br>Draw, describe |
|---|---|
| **Cobb angle** (if known) | **Rate of progression** (if known) |
| **Correctable Y/N** | |
| **Comments** (Include any action, spinal jacket – type and wear time, surgery) | |

## Appendix Three: E.K. Scale (wheelchair dependent)

| Classification | Measure | Score | Classification | Measure | Score |
|---|---|---|---|---|---|
| 1. Ability to use wheelchair | Able to use a manual wheelchair on flat ground, 10m < 1 minute | 0 | 6. Ability to use the hands and arms for eating | Able to cut meat into pieces and eat with spoon and fork. Can lift a filled cup (approx 250ml) to the mouth without elbow support | 0 |
| | Able to use a manual wheelchair on flat ground, 10m > 1 minute | 1 | | Eats and drinks with support at elbow (with tray) | 1 |
| | Unable to use manual wheelchair, requires power wheelchair | 2 | | Eats and drinks with elbow support; with reinforcement of the opposite hand +or – aids | 2 |
| | Uses power wheelchair, but occasionally has difficulty steering | 3 | | Has to be fed | 3 |
| 2. Ability to transfer from wheelchair | Able to transfer from wheelchair without help | 0 | 7. Ability to turn in bed | Able to turn himself in bed with bed clothes | 0 |
| | Able to transfer independently from wheelchair, with use of aid | 1 | | Able to turn himself on a couch, but not in bed | 1 |
| | Needs assistance to transfer with / without additional aids | 2 | | Unable to turn himself in bed. Has to be turned < 3 times during the night | 2 |
| | Needs to be lifted with support of head when transferring from chair | 3 | | Unable to turn himself in bed. Has to be turned > 4 times during the night | 3 |
| 3. Ability to stand | Able to stand with knees supported, as when using braces | 0 | 8. Ability to cough | Able to cough effectively | 0 |
| | Able to stand with knees and hips supported, as when using st. aids | 1 | | Has difficulty to cough and sometimes needs manual reinforcement. Able to clear throat | 1 |
| | Able to stand with full body support | 2 | | Always needs help with coughing. Only possible to cough in certain positions | 2 |
| | Unable to be stood, marked contractures | 3 | | Unable to cough. Needs suction or +ve pressure breathing techniques to clear airways | 3 |
| 4.Ability to balance in the wheelchair | Able to push himself upright from complete forward flexion | 0 | 9. Ability to speak | Powerful speech. Able to sing and speak loudly | 0 |
| | Able to move the upper part of the body > 30 in all directions from the upright position, but cannot push himself upright as above | 1 | | Speaks normally, but cannot raise his voice | 1 |
| | Able to move the upper part of the body < 30 from one side to the other | 2 | | Speaks with quiet voice and needs a breath after 3 to 5 words | 2 |
| | Unable to change position of the upper part of the body, cannot sit without total support of the trunk and head | 3 | | Speech is difficult to understand except to close relatives | 3 |
| 5.Ability to move arms | Able to push himself upright from complete forward flexion by pushing up with hands | 0 | 10. Physical well being | No complaints, feels good | 0 |
| | Unable to lift the arms above the head, but able to raise the forearms against gravity, ie. Hand to mouth with / without elbow support | 1 | | Easily tires. Has difficulty resting in a chair or in bed | 1 |
| | Unable to lift the forearms against gravity, but able to use the hands against gravity when the forearm is supported | 2 | | Has loss of weight, loss of appetite. Scared of falling asleep at night, sleeps badly | 2 |
| | Unable to move the hands against gravity but able to use the fingers | 3 | | Experience additional symptoms: change of mood, stomach ache, palpitations, perspiring | 3 |
| | | | | E.K. Total | |

## Appendix Four: Respiratory Chart for DMD

| Stage | Aim | Objective | Outcome measure |
|---|---|---|---|
| Young ambulant<br>(Diagnosis to approximately 10 years) | To maintain and promote good inspiratory capacity. | Encourage wind instruments, blowing bubbles, singing etc | Regular peak flow to monitor respiratory muscle fitness. Peak cough flow is a good way of measuring expiratory muscle function. |
| | To maintain and promote respiratory fitness | Encourage young people to maintain an active lifestyle within their capabilities. | |
| | To teach an awareness of breathing control | An incentive spirometer can be used to teach breathing control awareness | |
| Wheelchair dependent<br>(Approx 11-16 years) | To maintain chest compliance | Increase persons awareness of improving lung volume recruitment such as breath stacking/ and /or glosopharyngeal breathing. Teach parents /carers how to increase inspiratory measures using an ambu bag. | Regular assisted inspirations (aim for daily and this can be increased when young person has a chest infection))<br>Referral to Respiratory Consultant for formal monitoring<br>Referral to Orthopaedic Consultant for spinal assessment<br><br>Many patients with respiratory muscle weakness benefit from a prescription for antibiotics to be kept at home. Advise them to have a low threshold for commencing antibiotics when they develop a respiratory tract infection. |
| | To prevent chest infections | People with DMD are encouraged to have their flu and pneumococcal jabs where appropriate particularly if VC <50% of predicted value | |
| | To introduce effective measures for clearing the chest during infections | Respiratory assessment by physiotherapist to assess best method of clearing the chest (Active Cycle, Autogenic Drainage, Positive Expiratory End Pressure)<br>If peak cough flow is less than 280l/min teach cough augmentation techniques such as manual splinting of the diaphragm and thoracic holds.<br>Use of cough assist machine (mechanical in-exsufflator) if appropriate.<br>Early delivery of antibiotics during a chest infection | |
| | To prepare for non invasive ventilation (NIV) | Practice regular lung volume recruitment techniques with use of ambu bag | |
| | To monitor scoliosis | Refer to Edinburgh Sick Children's Hospital for monitoring of scoliosis. | |

| Stage | Aim | Objective | Outcome measure |
|---|---|---|---|
| Wheelchair Dependent on Non Invasive Ventilation (NIV)<br>Indications for ventilation<br>Poor FVC<br>Frequent chest infections<br>Poor Sleep Hygiene<br>Early morning well being<br>Poor Appetite<br>Weight loss<br>(see Epworth Sleepiness scale) | To prevent/manage chest infections | If cough is ineffective at clearing secretions,further techniquest to increase inspiration might be helpful such as an ambu bag or cough assist machine (mechanical in-exsufflator MI-E). The cough assist machine can be used in conjunction with manually assisted cough techniques. It can also be used to clear secretions in the absence of a chest infection and some patients like to use it prophylactically<br>If aspiration or weight loss is evident, refer to a speech and language therapist and / or dietician. | Liase with respiratory physiotherapist and breathing support /nursing staff. |
| | To maintain chest compliance | As above | |
| | To manage transition process. | Liase with adult physiotherapy teams | |
| Advanced stages<br>NIV and daytime ventilation for short / extended periods of time. | Ensure person and carers are able to clear chest effectively. At this stage, muscle weakness and fatigue are of particular concern in cough augmentation techniques. | As well as all of the above, a suction unit may be necessary. | Regular spirometry<br>Regular contact with breathing support team<br>Regular ventilator checks to monitor respiratory pressures.<br>Ventilator may be used in conjunction with chest clearing techniques. Discuss with respiratory physiotherapist. |
| Emergency admission procedure | To manage chest infection<br>To manage end of life care | | Preparation of advance directives should be encouraged in DMD. These can be discussed with the respiratory consultant or neurologist. |

| Symptoms of respiratory failure | Symptoms of nocturnal hypoventilation | Symptoms of Bulbar Dysfunction | Signs of respiratory muscle weakness |
|---|---|---|---|
| Shortness of breath<br>Orthopnea (Dyspnoea when lying flat)<br>Recurrent chest infections<br>Lethargy<br>Weight loss | Frequent nocturnal wakening<br>Excessive daytime sleepiness<br>Reduced concentration<br>Un-refreshing sleep<br>Fatigue<br>Early morning headache | Nasal regurgitation<br>Choking or coughing episodes at mealtimes<br>Weak cough<br>Recurrent chest infections | Weak sniff or cough<br>Abdominal paradox<br>Recruitment of accessory muscles at rest<br>Increased rate of respiration<br>Reduced chest expansion<br>Cyanosis<br>Papilloedema (severe hypoventilation) |

**Appendix Five**
**Epworth sleepiness scale**

| SITUATION | CHANCE OF DOZING |
|---|---|
| Sitting and reading | _____ |
| Watching TV | _____ |
| Sitting inactive in a public place (e.g. a theatre or a meeting) | _____ |
| As a passenger in a car for an hour without a break | _____ |
| Lying down to rest in the afternoon when circumstances permit | _____ |
| Sitting and talking to someone | _____ |
| Sitting quietly after a lunch without alcohol | _____ |
| In a car, while stopped for a few minutes in traffic | _____ |

| |
|---|
| 0 = no chance of dozing |
| 1 = slight chance of dozing |
| 2 = moderate chance of dozing |
| 3 = high chance of dozing |

**If score is between 6 and 8 there are some concerns with sleep hygiene. Scores of 9 or above are considered significant and patient should be referred to his respiratory specialist.**

**Appendix Six**
**Lung Volume Recruitment Techniques**
In order to successfully expel secretions from the lungs the patient requires a good expiratory volume and a forced expiration. In DMD the respiratory muscles and diaphragm are severely compromised by weakness and many patients are unable to successfully increase lung volume and forcefully expire air.

In order to maximise respiratory volume the patient can use a number of techniques to increase lung volume recruitment:

- Glossopharyngeal breathing
- Breath stacking with assistance of
    - an ambu bag
    - mechanical in-exsufflator (cough assist0
    - ventilator

**Glossopharyngeal breathing**
This requires good bulbar control and some patients can develop this technique naturally. It involves 'gulping' air into the lungs and breath stacking. Patients who require daytime ventilation can use this technique to come off their ventilator for bathing and showering etc whereas others use it to add volume to their voice.

**Ambu Bag**
An ambu bag fitted with a one way valve is recommended (available from Intersurgical,0118 9656376 or www.intersurgical.com). These ambu bags are also known as lung volume recruitment ambu bags. (Always mark ambu bag with a notice "Not to be used for resuscitation).

Current recommendations are that it should be used up to four times per day for those who have an ineffective cough. Aim to use it first thing in the morning to clear secretions that may have gathered overnight and again last thing at night. It is also recommended that the ambubag is used before meals however if bulbar control is poor and patient is likely to aspirate, it may be beneficial to use after eating. Refer to suppler for infection control / use of filters.

It may be also be helpful to use it more often if patient requires to cough or if there is a chest infection however avoid overuse as patient can become fatigued. Early use of antibiotics is essential if a chest infection is suspected.

**Technique**

- Clear explanation should be given to the patient
- Best done in sitting but can be done in lying or a semi-recumbent position. Head should be supported against a headrest and if in the wheelchair, ensure that the brakes are on and chair is positioned against a wall particularly during assisted cough.
- Position nose clip if tolerated
- Ask patient to take a deep breath in and hold
- Immediately place mouthpiece into mouth and ensure there is a good seal.
- Gently squeeze bag and instruct patient to take a second deep breath
- Repeat again if possible. In this way the patient is stacking breath on breath until lungs are full. The patient may adapt more readily if LVR is initiated at the end of normal exhalation. As chest expands, the patient will feel a stretch in his chest.
- Exhale or cough as desired.

Encourage the patient to take as much air as possible and maintain eye contact throughout the treatment. Watch for initiation of inspiration so the helper can time the squeeze on the ambu bag. If air leakage is a problem, change interface to a mask if preferred. This technique should not induce dizziness or chest discomfort – in the event of these symptoms occurring, discontinue treatment.

**Mechanical in-exsufflator (Cough assist)**

As with the ambu bag, the cough assist machine will deliver a positive pressure inhalation but will deliver it throughout the inspiratory cycle. This can be administered via a mask or mouthpiece. The machine very quickly changes to negative pressure and forces expiration. This expiration can be done in conjunction with manually splinting the diaphragm for a more effective cough.
These machines are becoming more popular as assistance from one helper is required but two helpers may be necessary for the ambu bag technique and assisted cough. Also the additional negative pressure during expiration can be enough to clear secretions without the need for a forced assisted cough. Many clients report that the cough assist helps with secretion clearance without the same degree of muscle fatigue as other techniques.
The cough assist machine also has the capacity for automatic or manual timing of the inspiratory, expiratory and pause phase.

**Assisted cough**

When undertaking an assisted cough, some patients find it more comfortable to dissipate the force required during the upward thrust by using a towel or small cushion across the abdomen.
For an international review of respiratory literature refer to https://eshare.bah.com/sites/CDC_SGCC/default.aspx

## Appendix Seven
## Spinal Fusion

Around 90% of boys with DMD will develop a scoliosis and in recent years, this figure may be higher due to the fact that these young men are living longer. Monitoring the scoliosis should commence before the loss of ambulation to enable surgical intervention to be offered at the appropriate stage if the young person is a suitable candidate for this procedure. The orthopaedic consultant will monitor the Cobb angle and surgery is best undertaken when this angle is between $20^0$ and $40^0$ although in some instances, the spinal team may operate well before the scoliosis reaches this level. Spinal surgery is a complicated procedure and families can feel very stressed around this time. Prior to spinal surgery, good preparation is essential. If the young person does not have a tilt in space wheelchair, it is highly recommended that this is in place before hospital admission. Advance planning is essential as delays in the provision of equipment are not uncommon.

After spinal fusion, the young person may be taller and therefore lateral supports / back support contours may not be at the correct position. It is recommended that the young person has a complete re-assessment of their wheelchair / seating provision and if this can be pre-arranged for 2/3 weeks after surgery, then this will avoid delays when waiting for an appointment with local seating services.

The young person may have difficulty with head control as he will be in a different position therefore adequate head support is essential. For the first few weeks the young person may not feel comfortable sitting upright and the tilt and/or recline function in the wheelchair / shower chair will be beneficial. Some young people lose the ability to feed themselves as their 'trick' movements are more difficult and the hand has to lift the food to the mouth through a greater distance against gravity. Loss of this ability can be distressing for the family as well as frustrating for the young person. Increasing tray and table heights can alleviate this situation however, in some instances the young person may not resume independent feeding.

Hoisting both at school and at home is essential and manual lifts are not recommended particularly in the first year after spinal fusion. Bone grafts can take between nine and twelve months to heal and during this time particular attention should be given to moving, handling and postural management. The hoist sling should support the head and neck and slings with strengthening in the back are generally best. In some cases, it is best to avoid excessive hip flexion beyond $90^0$ particularly in the first nine months and the spinal consultant will be able to further advise on this. In some cases the pelvis is also fused to the spine and excessive hip flexion can increase the strain in the lower back through flexion of the lumbar spine. Each consultant will manage the spine differently and it is important to check the post-operative care with the consultant in charge.

Rotation at the spine should be avoided as this can place undue stress on the healing spine. 'Log' rolls are recommended and a symmetrical sleep posture is desirable. Appropriate sleep support in terms of pillows or pressure redistributing mattresses are generally necessary once the young person is no longer able to turn in bed independently and this may have to be reviewed following surgery. Changes to sleep posture may be best undertaken in incremental stages and consideration to respiratory function and how this may be affected by positioning is important especially in those with very weak respiratory muscles who require non-invasive ventilation. Care and attention to hip joints is also recommended through 24-hour postural management.

Physiotherapy such as passive movements to hip joints through their full range should be discussed with the spinal surgery team as should hydrotherapy and sporting activities as some wheelchair activities may have to be postponed until the spine is fully healed. In most circumstances, activities can be resumed after 6months with supervision, as falls out of the wheelchair must be avoided. If there are any queries or concerns with specific activities then please discuss with the young person's spinal consultant. When it is known that a young person has been accepted for spinal surgery, local physiotherapists are advised to contact the Clinical Specialist in Spinal Surgery, Edinburgh Sick Children's Hospital, Sciennes Road, Edinburgh EH9 1LF Tel:0131 536 0000 Bleep:9126

## Appendix Eight
## Exercise

Muscle weakness is defined as the reduction in strength of one or more muscles and can be subjective or objective in nature. It can also be exhibited as fatigue, exhaustion or debility (www.nim.nih.gov/medlineplus/ency/article/003174/htm). The Physiotherapist is responsible for providing advice on exercise and activity in the person with Duchenne Muscular Dystrophy (DMD). This should be tailored to the person and stage of their condition. Persons with DMD should be encouraged to be active in normal, age appropriate activities and sport within the limit of fatigue. There is a paucity of evidence regarding the effect of exercise in persons with DMD. The numerous benefits of exercise, including social and psychological, are well recognised by specialist clinicians (Eagle, 2002).

| **Intervention** | **Recommendations** |
|---|---|
| Aerobic activity | Normal, age appropriate activity, including play in children, should be encouraged. Also recommend non-weight bearing activities such as swimming, cycling, horse riding. Research into aerobic and anaerobic exercise in children with DMD has not been shown to influence functional ability. |
| Eccentric exercise | Prescription of eccentric activities are not recommended because of the evidence reported in animal studies. Studies report eccentric exercise leads to increased muscle damage (Eagle, 2002). Examples of eccentric activity to avoid include heavy resisted activities such as weights, unnecessary walking downstairs and running downhill. |
| School based exercise | Children with DMD should be encouraged to participate in Physical Education lessons and other school sports within limits of their fatigue. Sports and classroom teachers should receive guidance from the child's local Physiotherapist |
| Disabled Sports Association | Children and their families may be referred to a local organisation for participation in appropriate sports. This may include horse riding, WC sports |
| Hydrotherapy | Recognised as beneficial for people with DMD and recommend if available. In the absence of the service, families should be encouraged to pursue warm water activities. Due to a paucity of evidence, this has been extrapolated from other neuromuscular disorders Grade |
| Parents | It is the responsibility of the Physiotherapist to provide guidance, education and recommendations regarding appropriate levels of activity. For example, awareness of the dangers of fatigue or periods of inactivity should be discussed. |
| Over exercise | Therapists should be aware of the risk of over exercise which may result in myoglobinurea. This is particularly relevant in children who are on steroids. |
| Steroids | The introduction of steroids as standard treatment may be a factor in increased frequency of myoglobinurea, as children are more active. DMD boys are known to be osteoporotic and this may increase with the long term use of steroids. Long bone fractures are particularly common when ambulation is becoming more difficult and this may lead to complete loss of ambulation. Therapists should be aware of the possibility of fractures particularly prior to the loss of ambulation when they are more unstable. |

## Stretching

For many boys with DMD, contractures are a part of the condition. The disease process causes muscle weakness. The link between muscle imbalance and contractures has not been established however, there is an association between them and long term positioning and posture. The development of joint contractures and deformity can also be associated with pain. Promotion and maintenance of muscle length and joint ROM is recognized as essential. Stretching is defined as a prolonged passive movement applied to the muscle at the end of range

| **Intervention** | **Recommendations** |
|---|---|
| Early implentation of a tailored stretching programme where tightness at end of range is noted. | Assess all four limbs for joint tightness. Early implementation of a stretching programme in is an integral part of the physiotherapy management of DMD particularly the gastrocnemius complex. It is recommended that stretches commence when the child has less than $20^0$ dorsiflexion.<br>NB Upper limb contractures can occur in ambulant children i.e. tightness in long finger flexors or supinators.<br>Self stretches, passive and/or active assisted should be tailored to the individual and be introduced once there is loss of normal range across a joint.<br>The MDC Physiotherapy guidelines booklet is a useful resource as it has pictures of common stretches |
| | The first muscle groups at risk of contracture are recognised as gastrocsoleus complex, hip flexors and iliotibial band (Eagle, 2002). Utilise 24 hour positioning and appropriate equipment in addition to stretches. Standing wedges may be useful to stretch the gastroc/soleus complex |
| | Other muscle groups of the lower limb are at risk of developing contractures at a later stage. Monitor muscle length in all groups of the lower limb and implement additional stretches as appropriate |
| | Upper limb is at risk of development of contractures. Generally, this occurs in the non-ambulant stage, but not exclusively. Monitoring of the muscle length of the upper limb is essential from an early age |
| | There is no evidence to prescribe the exact frequency of stretches, length of hold etc however, normal muscle responds to 20secs of stretch. In practice, maintaining a stretch of 20sec may be difficult in the person with DMD however, clinicians do agree on a daily programme where possible. |
| | Symmetry to be promoted in posture, exercises and activities |

## Orthoses

Night-time AFOs can be utilised from an early age to provide a sustained stretch of the gastroc/soleus complex, with the aim of maintaining ROM at the ankle. There is evidence to support use of AFO's for night-time. Scott et al., (1981) conclude that early and persistent use of AFO,s at night delays tendo-achilles contractures and enhances walking ability. Hyde et al., (2000) concludes AFO's and stretching are more effective in control of a tendo-achilles contracture compared with stretching alone.

| Intervention | Recommendations |
|---|---|
| Night splints (AFO's) | There is no evidence for the timing of the intervention but there is a consensus for the introduction of AFO's when ankle power is reduced or loss of range of motion into dorsiflexion is noted. Expert opinion agrees on early introduction and nightly use. Care must be taken if there is lining in the splints and the risk of infection should be considered. Night splints should be extended beyond the metatarsal heads. |
| Day time AFOs | There is no evidence for use of daytime AFO's in the ambulant child. Solid AFO's prevent the dynamic equinus which is an essential compensation to maintain independent gait. Insoles may assist in providing stance phase control of the foot. Non-ambulant patients should utilise day time AFO's to maintain good foot posture and promote supported symmetrical sitting in a wheelchair. Day time AFO's should be supplied at the time of loss of ambulation. Trimlines may be behind the metatarsal heads for ease of donning footwear. DAFO's are not often recommended. |
| KAFOs | KAFO's are not often used in Scotland. Assessment of suitability should take place following discussion with specialist muscle clinic team |
| Other splints | Contracture correction devices can be utilised for the upper and lower limbs. Occupational Therapy should be consulted for advice regarding upper limb splints. |

## 24 hour Postural Management

Physiotherapists have a crucial role in the assessment and management of posture in lying, sitting and standing.

Postural management is defined as "the use of any technique to minimize postural abnormality and enhance function" (Clark et al, 2003). It includes physiotherapy management in the form of stretches, and passive movement as well as within the prescription of equipment, orthoses, medication and surgery.

24 hour postural management may be best introduced prior to the onset of contractures and deformity. Many therapists undertake postural management at different levels and intensity from diagnosis in the form of night splints, in soles, stretches and advice on seating and posture.

Postural management is best delivered in such a way that it encompasses rest, recreation and activity. It acknowledges that static postures can be detrimental to the maintenance of function and that a variety of different postures are adopted throughout the day that will include asymmetrical positions. It also acknowledges the fact that prolonged static postures can be destructive and a variety of different postures may be a useful goal.

## Standing

Once standing posture becomes compromised, it may be useful to introduce specific standing support as often as is able.
This may occur when:

- Gastrocnemious / soleus complex becomes tight
- Heel contact is lost when stationary
- There is asymmetrical standing posture
- When child is unable to stand still and /or standing balance is compromised
- The child is no longer able to stand independently

Initially, a standing frame may be appropriate for those still able to move independently or with some assistance. Some centres may use tilt tables however moving and handling should be assessed in all situations. For those requiring maximal help, sit to stand wheelchairs or powered sit to stand frames may be more appropriate.

There are many benefits associated with continued standing which include management of contractures, osteoporosis as well as maintaining good spatial awareness and self esteem however, if comfort is compromised and pain is evident, standing may need to be discontinued. As with all treatments patient partnership and informed consent are essential.

For those children when loss of walking is imminent, an informed decision has to be reached whether or not to continue standing with supportive equipment. It is important to ensure equipment is provided quickly, prior to the onset of contractures.

For those children with hip and knee contractures, there is no consensus as to when it is no longer appropriate to stand. Care should be given to position within the standing frame particularly hyperextension of the lumbar spine.

In some situations, appropriate orthoses may also be worn in the standing position.

## Lying

Patients are generally reluctant to accept support in bed until independent changes in position are no longer possible however, by this time contractures may already exist. Lying postures can become problematic when

- The child is no longer able to change position independently
- The child requires frequent turning / changes of position through the night resulting in disturbed sleep for both his parents and himself.
- The child experiences pain from pressure or joint pain generally caused by weak muscles not being able to provide adequate support to the joints in certain positions

Patients are best when supported in a symmetrical position. This can be in side lying or supine however, there are pros and cons with each position. RCN recommends supine lying with $30^0$ turns to prevent an increase in pressure on the greater trochanter.

Prior to the start of ventilation, side lying may be best for respiratory purposes as airways are more likely to be able to remain patent. The diaphragm is more efficient in side lying however care must be given to ensure that the child spends equal amounts of time on either side. A preference on single side lying results in an asymmetrical thorax and often there can be difficulty when the young person commences supine lying when ventilation is required.

Supine lying enables the young person to ventilate both sides of his chest equally. It is often easier to maintain the head in midline avoiding asymmetrical contractures at the neck and hip joint integrity can be maintained with the use of pillows / positioning equipment.

Pressure re-distribution can be achieved using specific mattresses and if pressure is problematic, specific advice from the tissue viability service may be helpful. Visco elastic foam mattresses can be useful with pressure re-distribution however it should be noted that an increase in temperature can result. Sheets with a two way stretch are advisable to ensure that the sheet does not tighten underneath the young person hence increasing pressure and cotton bedding and nightwear for temperature control is advisable.

In later stages, boys with DMD are unable to undertake heat avoidance strategies by altering the bedding therefore care should be taken to maintain the bedroom at a constant temperature.

Pillows should also contain pressure re-distributing material to ensure that pressure areas do not develop on the back of the head (when supine lying) or ear (in side lying).

## Sitting

It is acknowledged that sitting is a posture in which all activities are undertaken whether rest, recreation or work. Sitting with an anteriorly tilted pelvis (forward sitting) is required for working whereas a posteriorly tilted pelvis is accepted as a position for rest and relaxation. Chairs that tilt and recline whether a wheelchair or static chair are advantageous as they facilitate independent changes in position through out the day.

It is important that physiotherapists are aware that hip dislocation and subluxation is common in DMD (Chan et al., 2001). Hip dislocation is secondary to pelvic obliquity which is secondary to scoliosis with muscle weakness as an important factor. Painful subluxation of the hip should be referred to an orthopaedic surgeon for advice.

## Appendix Nine
## Contacts

### 1. **Contact Details for working Group**

| | |
|---|---|
| Marina Di Marco<br>Clinical Specialist Physiotherapist (West of Scotland)<br>Neuromuscular Disorders<br>Ferguson-Smith Centre<br>Clinical Genetics<br>Royal Hospital for Sick Children<br>Dalnair Street<br>Glasgow G3 8SJ<br>E-mail: marina.dimarco@nhs.net | Jacky Yirrell<br>Clinical Specialist Physiotherapist (East of Scotland)<br>Neuromuscular Disorders<br>Department of Clinical Genetics<br>Western General Hospital<br>Crewe Road<br>Edinburgh<br>EH4 2XU<br>E-mail: Jacky.Yirrell@luht.scot.nhs.uk |
| Jane Tewnion<br>Neuromuscular Specialist Physiotherapist<br>Royal Aberdeen Childrens' Hospital<br>Westburn Road<br>Aberdeen<br>AB25 2ZG<br>E-mail: jane.tewnion@nhs.net | Anne Keddie<br>Armistead Child Development Centre<br>Kings Cross<br>Clepington Road<br>Dundee DD3 8EA<br>E-mail: annekeddie@nhs.net |
| Pierette Melville<br>Carnegie Clinic<br>Inglis Street<br>Dunfermline KY12 7AX<br>E-mail: pmelville@nhs.net | Lesley Harrison<br>Senior Physiotherapist<br>Rachel House Children's Hospice<br>100 Avenue Road<br>Kinross KY13 8FX<br>E-mail: lesleywotherspoon78@yahoo.co.uk |

2. The Muscular Dystrophy Campaign - www.muscular-dystrophy.org
Care Advisers: East:: Mrs Gill O'Neil- 0131 651 1018
West: Mrs Wilma Stewart - 0141 201 0656

3. Action Duchenne: http://www.actionduchenne.org/

4. Duchenne Family Support Group – www.dfsg.org.uk

5. Sleep Scotland, 8 Hope Park Square, Edinburgh, EH8 9NW Tel: 0131 651 1392. E-mail: sleepscotland@btinternet.com