A HOME EXERCISE BOOK

Physiotherapy Management for Duchenne Muscular Dystrophy

Muscular Dystrophy Campaign

Supported by Somerfield

FOREWORD AND ACKNOWLEDGEMENTS

In 1993 the Muscular Dystrophy Campaign (then the Muscular Dystrophy Group) published *Duchenne Muscular Dystrophy: A Parent's Guide to Physiotherapy in the Home*, written by Sylvia Hyde F.C.S.P. Although out of print for more than five years, there has been a steady and continued demand for the book to be reprinted, from families of children with Duchenne muscular dystrophy.

Much of this publication is based on that earlier book but updated in the light of our increased understanding over the last ten years of the effects of exercise and physiotherapy on patients with Duchenne muscular dystrophy. This booklet also incorporates material from an Australian publication by Helen Posselt, *Duchenne Muscular Dystrophy, A Team Approach to Management*[1].

We are indebted to Lyn Hemmings, Superintendent Paediatric Physiotherapist at the Children's Centre, Frenchay Hospital in Bristol who updated the book and advised the illustrator. Lyn works within a specialist muscle clinic providing physiotherapy assessment to a large number of children with Duchenne muscular dystrophy.

We would also like to thank the specialist physiotherapists who kindly reviewed and commented on the material in this publication and Somerfield Group Ltd for its financial support.

1. *Duchenne Muscular Dystrophy, A Team Approach to Management,* Montrose ACCESS, 2001

CONTENTS

STRETCHES AND EXERCISES (enclosed sheets)

1. INTRODUCTION

This book is intended to support the practice of physiotherapy at home for children and young people with Duchenne muscular dystrophy.

WHAT IS PHYSIOTHERAPY?

Physiotherapy is the physical treatment and management of a disease or condition which enables people to reach their maximum physical potential. Physiotherapists help to ensure that their patients lead as fulfilling a life as possible by advising children, famiies, carers and school staff about how the condition affects physical development.

In Duchenne muscular dystrophy, the physiotherapist will help to:

- Minimise the development of contractures and deformities through a programme of stretches and, where appropriate, exercises
- Anticipate and minimise any secondary physical complications
- Identify and prescribe aids and equipment (orthoses, callipers, wheelchairs and standing frames, for example)
- Advise on moving and handling issues
- Monitor respiratory function and advise on techniques to assist with breathing exercises and methods of clearing secretions.

PHYSIOTHERAPY AT HOME

The exercises recommended by your physiotherapist need to be done regularly if they are to be effective. This means developing a routine at home.

Any physiotherapy regime should be based on:

- The needs of your child
- The advice of your physiotherapist[2]
- The needs of the family (a practical routine to suit your family's lifestyle).

2. If you do not have access to specialist physiotherapy for Duchenne muscular dystrophy and you, or your physiotherapist, would like advice and support, contact the Muscular Dystrophy Campaign for information to help plan a programme tailored to your child's needs.

It is important that any routine is right for you and your child and, where possible, fits in with other family activities. If mornings are hectic, for example, it may be best to have a physiotherapy session during the evening, at bed or bath time. When the exercises are done is not important as long as they are part of an established routine.

Although the exercises should never be painful, stretching exercises may cause the muscle to feel different and your child will need to become accustomed to this. Some children will be able to do self-stretching exercises, as well as exercises with a carer, and a physiotherapist can help with this.

There has been some concern that over-activity, such as exercising with weights, may cause more harm than good to a child or young person with muscular dystrophy. Exercise should be at a moderate level[3] and not cause extreme or severe fatigue. Any activity that a child does voluntarily, and without becoming over tired, will have a positive effect.

MUSCLES

Muscles allow us to move, stand, and perform the range of movements needed for daily living. Each muscle is made up of fibres, although the type and amount of fibre varies depending on the sort of work the muscle does. The muscle fibres we use for standing are, for example, different to those in the muscles used to make fine, quick, finger movements.

Muscles are attached to bones via specially adapted parts of the muscle, called tendons. A muscle spans at least one joint and a movement occurs when it contracts or shortens. Muscles and their tendons are normally very flexible, allowing movement through lengthening and shortening. Usually when one muscle contracts or shortens the opposite muscle lengthens.

In Duchenne muscular dystrophy, muscle fibres break down and are replaced by fibrous and/or fatty tissue causing the muscle to gradually weaken. The rate at which this happens can vary between children with the same condition. Some muscles will be affected earlier than others and, if one

3. A Moderate Level (borg scale 3-4) is feeling warmer, breathing faster but still able to hold a conversation.

muscle weakens sooner than another, it can upset the normal balance of strength and cause contractures.

CONTRACTURES

When muscles are not used or become weak, they lose their stretchiness along with the associated tendons and ligaments (the tissue around the joints which connects bones, and controls the extent or range of movement). The joint becomes stiff and tight, usually more in one direction than the other. When a joint becomes fixed in one position, this is known as a contracture, and a deformity may occur.

As soon as possible after diagnosis, seek advice about physiotherapy and start treatment and management aimed at preventing contractures. Take action before there is any tightness or obvious deformity.

The most frequent contractures for children in the early stages of Duchenne muscular dystrophy occur at the ankles and hips. These are partly caused by the walking position which the child adopts – on the toes with feet apart – to maintain balance as the hip, knee and trunk muscles weaken. Children in the later stages of the condition spend more time sitting down which increases the tendency to develop hip, knee and ankle contractures.

ADAPTING TO CHANGES

Because a child with Duchenne muscular dystrophy will go through various stages of development, the physiotherapy you do at home should reflect these changing needs.

In **early developmental stages** the child will enjoy acquiring gross motor skills (movements which use the large muscles of the body), such as crawling, rolling, walking, cycling on adapted trikes and maybe running and jumping. All these activities provide good opportunities for learning and development but some will need to be adapted as the child loses strength and tires more easily. Over time, the child's skill acquisition and strength will level out.

During this stage of the child's development it is important to encourage activity that does not cause extreme or severe fatigue. Parents or carers may want to consider introducing a physiotherapy and exercise programme that includes:

- Regular stretches – self and/or manual stretches as well as passive stretching – for the muscle groups that are tightening (tendo-achilles, hamstrings and iliotibial band)
- Swimming, hydrotherapy
- Wearing orthoses (splints) at night to slow down contractures in the ankles.

In the **later developmental stage**, there will be a progressive loss of function. Although the child will be walking for periods of time, he or she will also require a wheelchair for mobility, especially over long distances. There is a range of equipment that can be used to help the child, such as electric or manual wheelchairs, standing frames etc. Any equipment should be thoroughly assessed by a qualified professional before it is used. The upper limbs will also be weaker but daily function activities should be encouraged.

A physiotherapy programme at this stage may include:

- Regular passive stretches for tendo-achilles, hamstrings, hip flexor and iliotibial band muscles; some self-stretches may also be recommended
- Stretches to the upper limb muscles
- Swimming, hydrotherapy
- Wearing orthoses (splints) at night
- Prone lying and other good positioning.

Physiotherapy advice and support continues throughout the **wheelchair stage**. Both good posture and a manual stretching programme are still important.

A physiotherapy programme at this stage may include:

- Regular stretches to minimise the development of contractures in hips, knees and ankles and ensure comfort in bed, ease in dressing and positioning in wheelchair
- Stretches for the upper limbs to minimise contractures
- Using a standing frame
- Prone lying and other good positioning

- Swimming, hydrotherapy
- Use of orthoses.

Physiotherapy support may need to be adjusted following any surgery for scoliosis. In particular, the wheelchair may need adapting to accommodate the child's improved posture.

HOW TO USE THIS BOOKLET

This booklet provides guidelines and instructions on how you can use physiotherapy to help your child with Duchenne muscular dystrophy.

All the stretches and exercises are on separate sheets so they can be combined, on the advice of your physiotherapist, into an individual physiotherapy programme that suits your child's needs. Any routine should be reviewed regularly as the needs of your child change.

The stretches, exercises and guidance included in this booklet are general, and additional ones may also be recommended.

2. EXERCISE

It is natural to worry about how much exercise your child should do and whether it's possible to do too much or too little. Finding a balance can be difficult and very often your child is in the best position to say how much is right for him or her. Exercise should never be done to the point of extreme or severe fatigue, although it is unlikely that you could persuade your child to do this.

Research from the British Heart Foundation indicates that all children should exercise at a moderate level [4] for at least one hour a day. A child with Duchenne muscular dystrophy should be able to exercise on a daily basis.

Walking is good exercise and should be encouraged whenever possible, although this can be difficult if your child falls frequently. Children with muscular dystrophy may tire more quickly but can walk for some distance and time if they are not rushed. They may struggle to walk uphill, downhill, and on uneven surfaces, such as sand or grass. Using a wheelchair for longer distances can alleviate tiredness, enabling your child to enjoy him or herself more on arrival.

It is important to not limit your child's play by being too overprotective. Physical and appropriate sporting activities can be beneficial to a child with Duchenne muscular dystrophy, helping to maintain strength and increase self-confidence. Swimming, horse riding (depending on muscle strength), bicycling, tricycling (there are low geared tricycles available) and other general activities all help children to relax, enjoy themselves and socialise with their peer group.

Swimming is particularly good exercise at all ages, both for the muscles and the lungs, and children may be able to swim or take lessons at school. It is important that children with muscular dystrophy stay warm in the water, either by continually moving or perhaps by using a children's pool, which is often warmer than a full size pool. The changing facilities also need to be warm, as well as accessible, to prevent the children becoming cold when they leave the water.

4. A Moderate Level (borg scale 3-4) is feeling warmer, breathing faster but still able to hold a conversation.

Children need to be as active as possible and not spend too much time sitting in front of the television, computer or using electronic games. They could play computer games while standing at a table, or lie on their tummy to help stretch the hips while reading or watching television. Encourage at least one activity a day that involves some exercise. It may be difficult in winter to find a suitable activity, but children can still help with household tasks such as tidying bedrooms or setting the table.

BREATHING EXERCISES

Breathing exercises become important as the child becomes less able to actively exercise.

When we breathe in (inspiration), muscles lift the rib cage up and out, making the chest larger. Air then rushes into the lungs to fill the extra space created. When we breathe out *(expiration*) the muscles relax and the air is pushed out by the elasticity of the lungs. We only use muscles of expiration when air is forced out, as in coughing.

As the respiratory muscles weaken in children and young people with Duchenne muscular dystrophy, this reduces the ability to inhale and exhale air forcefully. It becomes more difficult to cough and expel mucus from the lungs, which affects the amount of oxygen in the body and increases the likelihood of chest infections.

Research findings vary about the effectiveness of respiratory muscle training in children with Duchenne muscular dystrophy. Some suggest that devices which introduce resistance – such as an Incentive Spirometer – can be helpful. Certainly, it is a way to focus on breathing. It may also be helpful to encourage your child to play a wind instrument, the recorder for example, or join a singing group. Younger children could blow party blowers or bubbles.

3. GOOD POSTURE

Muscle weakness in key areas such as the spine and hips can affect the posture of a child with Duchenne muscular dystrophy.

Weakness of the spine muscles can cause scoliosis (curvature of the spine), and weakened hip extensor muscles cause lordosis (a pronounced inward dip of the lower back). When one side of the child's body is stronger than the other, this can create an uneven or non-symmetrical posture.

Your child may adopt unusual postures – in sitting, standing and lying – to compensate for muscle weakness, limited mobility and contractures. It is important to correct these postures because, if left, they can cause further problems, particularly in the spine. Good seating at all times helps to maintain good posture.

SITTING

The feet should be at a 90º angle to the legs when the child is sitting down. The seat of the chair should be firm and, ideally, not too wide. The back of the chair also needs to be firm and either upright or slightly slanting backwards (10º). The seat should be as deep as the thigh is long, so that the child is encouraged to use the back of the chair and not slump. The armrests need to be at the right height and not too far apart so that the elbows can be supported without causing hunched shoulders or leaning.

POSITIONING

The way a child moves and the positions adopted – to write, eat or rest, for example – are a direct response to losing muscle strength and having contractures. The child will naturally find the easiest and least tiring option, without thinking about it. Sometimes muscle strength and/or the stiffness of a contracture may be different on each side of the body. When this happens, an asymmetry or imbalance occurs which can cause scoliosis.

Passive stretching and night splints can delay the onset of contractures but it is important to know which positions to encourage and which to discourage, without nagging.

PRONE LYING

The prone lying position (face downwards) is good for resting. It can also help prevent contractures developing in the hips and knees. Prone lying can be combined with activities such as reading or watching television.

The child lies face down on a floor, couch or similar firm surface. Place a small pillow or wedge just *below* the hips (which should be level and the pelvis down) to encourage hip extension. The weight of the lower leg will straighten out the knees but it is important that the feet are free.

Discourage asymmetrical positions as these reinforce development of contractures and scoliosis.

STANDING

Standing helps bone density and posture as well as assisting in the management of contractures. It should be encouraged, during the day, for short periods (i.e. half an hour) or longer blocks of time (two or three hours if possible, but you need not be prescriptive).

When an older child or young adult finds it difficult to stand unsupported, but callipers are unsuitable, it may be helpful to use a **standing frame, swivel walker** or **tilt table**. They reduce the muscular effort required to stand upright and provide total body support, enabling the hip flexor, knee flexor and calf muscles to be fully stretched. Using a standing frame every day can delay the onset of scoliosis as well as aiding digestion and circulation. Children who have callipers often use these for standing.

NIGHT SPLINTS

As the name suggests, these are designed to be worn at night and are usually only for the ankles. They help slow down contractures by keeping the joint in the best position for the child. Night splints are made from a variety of materials, including polypropylene. The splint starts at the toes and finishes just below the knee. They must be comfortable and fit properly, as poorly fitting splints are unlikely to be worn and may prejudice the child against all splints.

Research has shown that using night splints in conjunction with passive stretching is the most effective way of delaying the development of contractures. Night splints are never, however, a substitute for passive stretching and should only be used in combination with stretching once there is an obvious feeling of tightness.

Day splints are very rarely worn by walking children as they can adversely affect mobility and make it more difficult to walk, climb, rise from a chair.

SLEEP SYSTEMS

When the child is unable to turn in bed at night, it is important that he or she is positioned carefully so that the hips are in a neutral position. There are a range of sleep systems, which can help prevent pressure areas from developing and keep the child in a good position for longer. A sleep system can also reduce the number of times parents need to turn the child, thereby improving the quality of life for all family members. Your physiotherapist can conduct a sleep posture assessment to determine whether a sleep system is appropriate for your child's needs.

4. MOBILITY

'What happens when walking becomes difficult?' is a question asked by all parents and an area of understandable concern. This chapter includes information on alternative choices and ways to help your child. Do not be afraid to also discuss this issue with your doctor and/or physiotherapist.

There are several signs that suggest your child could be finding walking more difficult. He or she may seem quieter and less inclined to join in with activities, teachers might report that your child is being left behind and the number of falls may increase. Falls are more likely to occur when the child is outside, negotiating uneven ground, slopes and kerbs. Falls are not necessarily caused by tripping; muscle weakness may make the child drop. If the trunk muscles are weak, for example, it can be difficult to make the necessary postural adjustments and the child can over-balance. Falling can also occur more frequently when the child is tired.

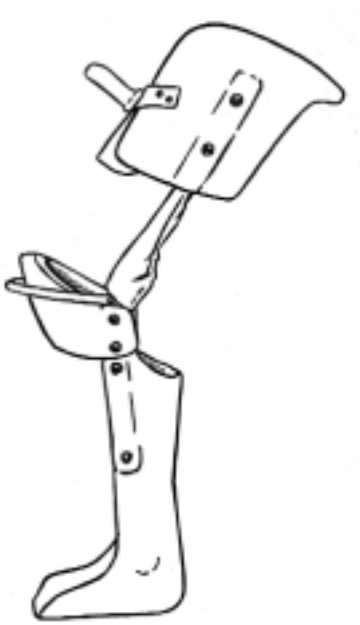
It may be apparent at your child's regular physiotherapy assessment that muscle weakness and possible contractures in the hips, knees or ankles are reaching a critical point. A sudden growth spurt, a bad fall or another illness may also precipitate loss of independent walking.

CALLIPERS (KAFOS)

Some children can carry on walking independently for up to two years or longer by using orthoses called **K**nee **A**nkle **F**oot **O**rthoses (KAFOs). This treatment was developed at Hammersmith Hospital, London, based on work done in Chicago, USA. The young person uses a wheelchair for long distances – as a car is used for speed and convenience – but walks short distances at home. Because children with Duchenne muscular dystrophy have muscle weakness in the arms, shoulders and trunk, they cannot use walking aids such as crutches.

A KAFO is an 'ischial weight bearing knee ankle foot orthosis', which makes use of the lordosis with which the child has become accustomed. It extends

from the toes to the hip and the child sits on, or is supported by, the lip at the top of the thigh piece. KAFOs are made of polypropylene and have a hinge which allows the knee to bend when sitting. No special shoes are required and they can be worn beneath trousers, so are fairly unobtrusive.



The decision to use orthoses must be made by both the family and child, based on information and advice from a doctor and physiotherapist. There are many things, unique to each child and family, which need to be considered and discussed, such as the number and age of other children in the family, lifestyle, personality, type of school and attitude of teaching staff etc. KAFOs will not be suitable for everyone and your child may choose to use a standing frame instead.

How are they fitted?

To fit the orthoses, the foot must be at a right angle to the leg. To do this, an orthopaedic surgeon usually releases the tight tendo-achilles (heel cord). This is a small operation, which generally causes very little pain. Your child's consultant or physiotherapist can explain what choices are available locally, or at the Muscle Centre you attend.

When to do it

Orthoses do not need to be fitted before the child has either stopped walking independently or is falling more frequently. It must be done, however, before the child has been dependent on a wheelchair for more than two or three months, and is best done when the child has only just lost the ability to walk independently. It is important to discuss the use of KAFOs well in advance of losing the ability to walk so that you know who to contact, what to do and when.

Who is suitable?

- The child with enough strength in the hips and trunk to balance
- The child who wants, and will accept, them
- The family who can manage.

What are the advantages?

- Independence in the home and classroom
- Being the same eye level as friends
- A delay in the development of scoliosis and contractures in the hips and knees
- Easier transfer between chair and car, etc.
- Easier toileting.

When the young person is unable to use the orthoses for walking they can still be used for standing, and help to make transfers easier between chair, car and bed etc.

WHEELCHAIRS

The majority of children with Duchenne muscular dystrophy will need a wheelchair for transportation and independent mobility, long before they have lost the ability to walk. Often two wheelchairs – one manual, one electric – are required, to suit life at school and home. Choosing the right wheelchair is absolutely essential for the child's well being. Technical decisions about seat size, seat cushion, back support, headrest, position of power controls, tilt-in-space facility etc, must be made with great care. Experts such as your physiotherapist and/or occupational therapist, the physiotherapist at the local muscle centre/specialist clinic, local wheelchair services, Disabled Living Centre, Whizz-Kidz assessor should be consulted.

It is essential that any wheelchair, once in use, is routinely checked and monitored so that it continues to meet the child's requirements. As the child grows and their physical condition changes, the wheelchair will need to be modified to offer additional support and maintain independence.

5. STRETCHES

It is very common in muscular dystrophy for muscles and tendons to tighten. Some muscles will be affected earlier than others. The first muscle to tighten is usually the calf muscle/achilles tendon at the ankle, but the muscles around the hips, knees, elbows and fingers can also be affected.

Contractures can make some movements and activities more difficult. Regular daily stretches help maintain muscle length and keep joints mobile.

Your physiotherapist can create an individual programme for your child from the exercises at the back of this book. The descriptions and diagrams are only reminders and anybody undertaking passive stretching must receive professional guidance and instruction.

There are three different types of stretches: passive, active assisted and self-stretches.

PASSIVE STRETCHES

Passive stretches are the cornerstone of physiotherapy management and an essential aspect of any programme, at all stages of the condition. It is never too soon to introduce passive stretching.

As the name suggests, the child does not actively take part in the stretching process. Passive stretches are done by a parent, carer or therapist. Slow and firm passive stretching will not harm the joint or muscle and can be done every day. Tight and/or shortened muscle tissue is stretched by moving the joint as far as possible and maintaining the position for at least ten seconds (your physiotherapist may recommend longer, depending on your child's needs). Done properly and effectively, passive stretching is not painful but your child will experience a sensation of pulling and be aware of gentle but sustained pressure being applied. Some children put up a mild protest at passive stretching but this is usually overcome once their confidence has been gained and a routine established.

It doesn't matter what time of day you do the passive stretching but most people find it helps to establish a routine that fits in with the other demands of family life. Make it a special time for the child, when the day's events can be shared and emotional ties strengthened.

It may help to do the stretching:

- After a bath
- With tapes or stories, singing, story telling
- After massaging the muscles to be stretched.

Position the child so that he or she is well supported and comfortable, and the joints not being moved are stabilised. The child must relax completely and not make any active movement or resist the stretch. If the stretching is done too quickly, the child is more likely to resist and become frightened.

Discuss and agree the duration of the stretch. Start the stretch gently and gradually increase to a maximum intensity, without pain. Overstretching should be avoided.

ACTIVE ASSISTED STRETCHES

Active assisted stretches are done by the parents with the child assisting the movement. When a joint becomes contracted, the tight tissue prevents the opposite muscle group from working properly. Active assisted stretches can stretch the tightened muscle and work the opposing muscle group at the same time.

Active assisted stretches are particularly useful for the ankle. While you stretch the Achilles tendon, for example, your child pulls up his or her toes. The harder you work together, the more effective the stretch will be. This form of stretching helps the time pass more quickly and makes the stretches less boring for your child.

SELF-STRETCHES

Self-stretches, as the name suggests, are stretches that the child is taught to do him or herself. These are most effective in children who are still walking and are particularly useful for the ankles, knees and hips.

6. BACK CARE FOR CARERS

Parents and carers can look after themselves by following some basic general rules:

- Always bend the knees and keep the back straight when bending down to pick something up
- Always be sure that you can manage the weight of whatever you are picking up
- Always hold whatever you are carrying as close to your body as possible
- Avoid carrying heavy loads up and down stairs.

One of the most common ways to incur a back injury is to 'lift and twist' (when lifting a child out of a bath or car, for example). Always plan the best way to lift something or someone, do not rush, and use available equipment to help.

Physiotherapists can advise you on safe ways to move your child and you can also consult the manual handling advisors and risk assessors at your child's school. If hoisting is recommended, your physiotherapist can refer your child to a social services occupational therapist (OT). Most doctors' surgeries also have leaflets on how to protect the back when lifting.

7. CHILDREN'S QUESTIONS

Q. What is the point of stretching exercises?

A. Stretching exercises are perhaps the most important exercises for all ages and keep your joints comfortable and moving. Athletes do these exercises to keep their muscles in shape.

Anybody who sits for a long time in the same position will get stiff and uncomfortable. Physios and doctors call this stiffness a 'contracture'. You may not have a problem bending your knee, but sitting down a lot can make it difficult to straighten up.

Joints that don't have a full range of movement can get achy and it's sometimes difficult to find a comfy position in bed. So best to just get on and do those stretching exercises!

Q. If my muscles are weak why can't I use weights to make them stronger?

A. Using weights won't make your muscles stronger because your muscles are different from other peoples. Overworking the muscle by lifting heavy weights could damage it. But there are other active exercises which you can do that are good for you.

Q. Why does my physio want me to go swimming or have hydrotherapy when I just think it's a pain getting undressed and dressed again?

A. Hydrotherapy is probably the best way to exercise if you have a muscle condition. The warm water supports your body and relaxes your muscles, which makes stretching exercises much easier. The best thing about swimming or hydro though is being able to move much more freely than you usually can and it's really good fun!

Q. What about my hands and arms?

A. Hands and arms need to be stretched too. Playing computer games is fun and your fingers need to be flexible in order to be an expert! Ask your physio what you can do (yes – it's more stretches!).

Q. What about my feet?

A. Looking good is important too. If contractures of the feet and ankle develop, this might make it difficult to wear the sort of trainers or shoes you prefer. Wearing splints will keep your feet in the right position so that you can look good (and yes, there are stretches that will help too!). The position of the upper leg is very important when looking at your foot posture. If your legs flop apart, your feet turn onto their sides (try it!).

Q. What if it gets hard for me to walk?

A. There is nothing wrong with using a wheelchair for some of the day to save energy for playtime. Keeping your legs stretched with the help of your physio or carer will help keep you walking for as long as you can. Even when it gets really hard, there are other ways to take those important steps, such as using callipers (KAFOs).

8. CONTACTS AND RESOURCES

CONTACTS

Muscular Dystrophy Campaign
7-11 Prescott Place, London SW4 6BS
Information line: 020 7720 8055
www.muscular-dystrophy.org
E-mail: info@muscular-dystrophy.org

Duchenne Family Support Group
37a Highbury New Park, London N5 2EN,
Tel: 0870 241 1857
Helpline: 0870 606 1604
www.dfsg.org.uk

Parent Project UK
Epicentre, 41 West Street
Leytonstone, London E11 4JL
Tel: 020 8556 9955
www.ppuk.org

RESOURCES

Giving a Face to Duchenne MD – Understanding the Disease, Guidelines for Care and Management (2 DVDs)
Includes musculoskeletal management.

Duchenne Muscular Dystrophy – A Team Approach To Management, book and two videos (one video is *An Overview of Physiotherapy Management*).
Produced by MontroseACCESS.
E-mail: information@montroseaccess.org.au

Books for children and young people
(available from Muscular Dystrophy Campaign)
Everybody's Different, Nobody's Perfect is aimed at four to ten-year-olds with a neuromuscular condition.

DMD On the Ball is aimed at teenage boys aged 10 to 14 who have Duchenne muscular dystrophy.

Hey, I'm Here Too is aimed at siblings of children with Duchenne muscular dystrophy.

9. GLOSSARY

GLOSSARY OF PHYSIOTHERAPY TERMS

Abduction – movement of a limb away from the body
Adduction – movement of a limb towards or across the body
AFO – ankle foot orthosis. In Duchenne muscular dystrophy this usually means night splints worn in bed to prevent the foot from pointing down
Assisted coughing – a technique used to help clear secretions on the chest
Asymmetry – when one side of the body is different to the other
Atrophy – decrease in muscle size and strength
Callipers – see KAFO
Cardiac – affecting the heart
Contracture – when a joint cannot move through full range because the muscles are tight
Distal – part of the limb the furthest away from the body (e.g. the hand or foot)
Dorsiflexion – pulling the foot up to a right angle
Extension – a straightening movement
Flexion – a bending movement
Hydrotherapy – water based exercise, usually done in a warm pool under the supervision of a physiotherapist
Hypertrophy – increase in muscle size, usually in the calf muscles (in Duchenne muscular dystrophy this is usually because the muscle contains a lot of fat)
Gastrocnemius – the calf muscle
Gluteal muscles – the buttock muscles, used to stand upright and climb stairs
Gower's sign/Gower's manoeuvre – a way of getting up from the floor into a standing position by pushing the hands on the legs
Gross motor skills – movements such as crawling, running or jumping which use the large muscles of the body
Hamstrings – the muscles at the back of the knee which help it to bend and also stabilise the pelvis
Ilio-tibial band (ITB) – the fibre on the outside of the thigh running from the hip to knee, which has muscles attached to it
KAFO – a shortened name for a **k**nee **a**nkle **f**oot **o**rthosis which extends from the toes to the hip
Lordosis – the extended position of the lower back, visible as an inward dip at the base of the spine, typical in children with Duchenne muscular dystrophy

Muscle biopsy – removing a small piece of muscle for examination
Night splints – made of polypropylene and worn at night to prevent contractures; usually start at the toe and finish just below the knee
Orthoses – another term for splints, callipers or anything worn externally to support the limb
Passive stretching – a technique used to stretch tight muscles by moving the joint as far as possible and maintaining that position
Patella – kneecap
Physiotherapy – the physical treatment or management of a disease or condition through a specially designed programme of exercising, stretching, positioning etc
Plantarflexion (of the foot) – pointing the foot down
Postural drainage – using physiotherapy to clear phlegm from the chest
Prognosis – the expected course and outcome of a condition or disorder
Pronation (of the forearm) – turned palm down
Prone – lying face down
Proximal – part of a limb nearest to the body (e.g. the shoulders or pelvis)
Quadriceps – the muscles at the front of the thigh that straighten the knee
Resistance – using weight or manual pressure to strengthen the muscles
Rotation – a movement which turns a part of the body
Scapula – shoulder blade
Scoliosis – sideways curvature of the spine
Spinal jacket – a corset or brace made of polypropylene or leather worn to keep the spine straight
Standing frame – equipment that holds the child in a standing position with minimal effort from the child
Steroids – drugs used primarily to treat muscle inflammation but also able to slow down deterioration of the muscle
Supination (of the forearm) – turned palm up
Supine – lying face up
Tendon – the fibrous part of the muscle which is fixed to the bone
Tendo-achilles (TA) – the large tendon at the back of the heel
Tilt tables – equipment that can take a child from a standing position to a lying position without any effort from the child
Walking frame – equipment, usually on wheels, designed to give the child stability while walking

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