NHS
Greater Glasgow and Clyde

Supporting Information Leaflet 12:

Ankle Management in Duchenne Muscular Dystrophy (DMD)

Introduction

Twenty four hour postural management is important throughout all the different phases of Duchenne Muscular Dystrophy (DMD). Postural management is looking after your posture when you are sitting, standing or lying. In DMD, your posture can be affected by your weak muscles as well as by the "dystrophic" process within your muscle so it is important that you develop an awareness of how best to look after your muscles throughout the different stages of the condition.

Some of the people who can help you look after your posture are Doctors, Physiotherapists, Orthotists, Occupational Therapists and Podiatrists. However, during your healthcare journey you will meet other healthcare professionals such as nurses and bio-engineers who can also help you look after your posture. These healthcare professionals are all part of the multi-disciplinary team who look after your health and well being.

Your physiotherapist will have shown you stretches and positioning and may have recommended insoles and orthoses (splints) for you to help look after your joints.

The joints that we pay a lot of attention to are the ankles, feet, hips, wrists and fingers as these joints can develop tightness from an early stage.

Contractures in Duchenne Muscular Dystrophy (DMD)

You will have heard the term "if you don't use it, you lose it"? When it comes to muscle, this is true for everyone. Muscles will shorten with lack, of use even if you don't have a muscle condition.

Our muscles do so much more than move our joints. They are vital to our immune system, our bone health and insulin (sugar) control.

If you are unable to move your muscles actively, then assisted movement or passive movement becomes an important part of your daily routine. Keeping the muscles moving is one of the primary aims of physiotherapy in the management of DMD.

Contractures occur when the muscles are no longer able to move the joints through the full range of movement. If we are unable to take the joint to the end of range, i.e. fully straighten the elbow or knee or hip, the muscles quickly learn that they are not needed to fully extend to the end of range and the ability to fully move the joint into the end of range is lost. **This loss of range due to muscle shortening is called a contracture.** In DMD, muscles develop contractures quickly due to the pathology within the muscle as well as the fact the muscles are weak and perhaps not strong enough to fully straighten the joint, so the joints are challenged from two areas.

In DMD, the muscles start to produce fibrous tissue which is an important part of the repair process when healing damaged muscle. However, as the muscle isn't able to repair itself due to the fact the dystrophin protein isn't working correctly, the repair process is always underway and never gets to a stage where the muscle is repaired. This means there is too much fibrous (scar) tissue in the muscle and the muscle will not work properly. At the same time, we see an increase in the inflammatory process which is also sparked by cell damage and this chronic inflammation within the muscle inhibits new cellular growth and repair.

What can we do?

Stretching

Whilst stretching may not completely prevent joint tightness, we are aware that those who perform stretching exercises regularly and use orthoses on a daily basis do manage to keep their joints in a better position for longer. Stretching and general movement are important for all the muscle groups and can help with pain and postural management. Your physiotherapist will have taught you the best stretches to do. We believe undertaking stretching in a variety of ways is best and stretching regularly throughout the day is a more effective way of carrying out the stretch. We think of stretches in the following ways:

Active Stretches

These are the kind of stretches that you would do by yourself. These can be done at any time through the day.

Passive Stretches

This is the type of stretch that someone else can help you with. You can get help with these stretches from a family member, carer or someone who knows you, and your condition. Your physiotherapist can show the person supporting you how to undertake these stretches effectively.

Static Stretches

These are stretches where your joint is held in a stretched position for a certain period of time i.e. standing in a standing frame, wearing a resting Ankle Foot Orthoses (AFO) overnight whilst you are sleeping, or for a period of time when you come in from school.

Progressive Stretches

This type of stretch occurs when the joint is moved into the range of movement that you can't normally get into by yourself. You can do this when someone is helping you stretch i.e. when they apply the stretch to your ankle or hip and then gradually increase the stretch.

You will feel the intensity of the stretch increase and can let them know that you feel you have reached the maximal stretch.

A progressive stretch also works when you have orthoses (AFOs) that are designed for this purpose. These may have hinges or adjustable straps to apply further stretching force. You can put the AFO on for around 15 minutes and then once the muscle has adapted to the position, you can increase the stretch until you feel you have reached a maximal stretch.

Serial Casting

If your ankle is very tight, we may recommend serial casting. This is when a plaster of paris (POP) is put on for 3-4 days and then removed. It is replaced by another POP for 3-4 days and this time the joint is stretched a little further. This process is repeated and generally there are three plaster changes in two weeks. The type of plaster you would have is a walking plaster, however, the plaster can feel quite heavy so you would not be walking as much as you do without the plaster. We would not continue with the stretching process for longer than two weeks as we are likely to have an impact on muscle strength as the ankle joint during this time is completely immobilised. This type of progressive stretching may be used when you are still walking and you are quite strong but the ankle has become very tight.

Stretching Hints and Tips

Stretches will very quickly become part of both you and your family's routine. For the best way to stretch we would advise the following:

- Always stretch when muscles are warm.
- Stretch tight muscle groups such as ankles, hips, long finger flexors.
- Undertake a variety of stretches such as active, passive, static and progressive stretches.
- Generally hold the stretch for 10–20 seconds (or for as long as is comfortable) to allow the muscle to get used to the length and do the stretch about 3 times.
- Static stretching can be undertaken within a standing frame or within a resting ankle-foot orthosis and this means you can do other things while you are doing your stretches.

Overnight resting splints

We may recommend overnight resting splints for ankles and in many cases this could be before we see a change in the range of movement at the ankle joint. Your physiotherapist will monitor your ankle joints, as well as your other joints, on a regular basis and will work with you to maintain the movement you have in your joints for as long as possible using the techniques we have already described.

Ankle - foot tightness

Ankle problems can start from an early age. Your posture has an effect on the position of your ankle in sitting and standing and this includes when you are walking. Sometimes that can be when you are standing for transfers or moving around on your feet for even small segments of the day. This will have an effect on your ankles. If the muscles around the ankle joint are weak or if the ligaments are a bit lax (we may say the ankle joint is hypermobile), the feet can roll inwards.

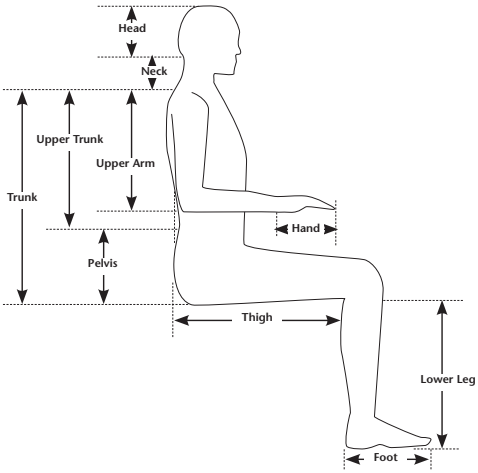
One of the “rules” in the treatment and management of conditions where the muscle are weak is if the muscles are unable to offer the joint adequate support (internal support), we will need to look for that help and support to keep your foot in a good position from an external resource, such as orthoses.

In cases of the feet, we would do this with the assistance of an insole. This insole could be across the whole foot (total contact insole) or just around the heel and mid foot depending on what is required.

If there is a greater degree of ankle instability, we may also suggest a “lycra” sock to give the ankle more stability.

If the ankle is unstable or the foot is not in a good position, muscle fatigue increases as the muscles are not only working hard to do the job of walking but they are also working to support the unstable joint.

What happens for those in a wheelchair?



Management of the ankle is every bit as important when you are in a wheelchair as it is when you are standing. This is because we still require to take weight through the plantar surface or sole of the foot when we are sitting. If we sit with our legs dangling, our pelvis is not getting the correct support to look after our back. We need to have good support at our pelvis and trunk if we are to use our arms effectively and efficiently and not become overly fatigued.

For many people, achieving this position is challenging as contractures may have developed however, a symmetrical position is something we would always work towards even if we are not able to be fully symmetrical.

It is also very important to make sure the thighs are in a good position as if they are too far apart and turning out, this will cause inversion (turning in) at the ankle joints. We always recommend wearing ankle foot orthosis when in the wheelchair to help prevent this type of deformity, as the ankle foot orthosis will support and maintain the ankle in an improved position.

Ankle Surgery

If your feet are unable to be corrected and cannot be placed on the wheelchair foot supports in a plantar grade position (feet flat on foot plates), issues can arise. We sometimes see a pressure area developing in the creases at the back of the ankle joint where the skin rubs against itself. Another common issue is an excess of callous formation or hard skin developing under the foot at the base of the little toe. This is because this area is taking too much weight
because the foot is turned in and unable to sit on the foot support in the correct manner. When a part of our body takes pressure that it is not supposed to but due to positioning cannot be helped, hard skin will often build in order to protect the fragile skin underneath. This is not only uncomfortable but when the ankle becomes fixed in this position, it is challenging to find shoes that will fit.

In order to achieve good sitting posture we may recommend a referral to an orthopaedic consultant to find out if surgery will change the position of the foot so it can sit flat on the foot support of the wheelchair. An orthopaedic consultant will review your foot to decide if foot surgery such as a tendo-achilles tenotomy or posterior tendon transfer will help.

This involves a general anaesthetic and casting or splints after surgery for pain relief and prevention of recurrence.
Without on-going splintage Achilles tightness can recur.

In the first two to four weeks after surgery, you will need a plaster cast to maintain the foot in the new lengthened position.

Whilst you were under anaesthetic, a cast will have been taken of your foot and we will make an ankle foot orthosis that is exactly the right fit for your new ankle position. Once your plaster is removed you will attend orthotics to have the new ankle foot orthosis fitted.

Following the removal of the cast, care of the scar site is important and your carer will massage it to keep it mobile and prevent it from becoming stuck down or fixed. It will also be important to re-start the stretches and passive movements that you did before your surgery as movement helps the healing process. This should not be painful but it may feel a little uncomfortable initially until you get used to it. A good place to start moving the ankle is in the bath or warm water or swimming pool if possible. Some people who have a hot tub at home have found this of great benefit after surgery in helping to get the ankle moving.

It is important that you wear the ankle foot orthosis through the day so your feet can be placed on the foot supports in your wheelchair. If you do not, your foot will start to point down and turn in again due to the dystrophic process that is going on in the muscle and all your hard work will be lost. Your physiotherapist can help advise on this.

It will also be important to have your seating reviewed. If your legs are turning out and falling to the side, this puts additional stress on your ankle joints and we would try to achieve a position where your thighs are parallel in the wheelchair. If your thighs continue to roll outwards it puts more stress on your ankle to turn inwards.

A symmetrical sitting position with your thighs parallel, or as close to this as possible, is preferable.

Conclusion

Looking after your joints throughout each phase of your condition is important to maintain good ongoing postural management.

Your physiotherapist will continue to assess and monitor you regularly through the growing stages and make changes to your management programme in order to best achieve good postural management. In physiotherapy we always work to the 80:20 rule. It's what you do 80% of the time that makes a difference so, as long as you are looking after your posture most of the time, it is okay to have the occasional time out if you forget your AFOs or are unable to do your stretches. Just return to your postural management

routine as soon as you can. If you start to feel your joints and muscles are getting tighter or there is a change in your posture be sure to let your physiotherapist know.

Further Information

If you have any questions about anything within this leaflet, please contact Marina Di Marco, Principal Neuromuscular Physiotherapist on:

0141 354 9205 or **marina.dimarco@ggc.scot.nhs.uk**.

My Physiotherapist is: