

Postural management and stretches:

Information for adults with Duchenne muscular dystrophy



Provided as a service to medicine by PTC Therapeutics
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West of Scotland Genetic Services and endorsed by the Adult UK North Star Physiotherapy Network.
This material is intended for adults who have been diagnosed with Duchenne muscular dystrophy.

Looking after your muscles and joints is an important part of daily care

As you become older, you and your family will, through experience, become experts in your care. This includes looking after breathing, bowel management and nutritional needs and keeping your bones and heart healthy.

An important part of managing your health is looking after the muscles and joints. As an adult, this can frequently be one of the more challenging aspects of care. There is often less access to physiotherapy than in childhood, and you will require more help with movement, stretching and posture. In addition, your daily routine may take longer than it used to and may leave you feeling more tired. This can leave less time for movement and stretching programmes as well as everything else in your life and juggling what is important to you can take a bit of thought. Building a programme that fits around your life is of the utmost importance.

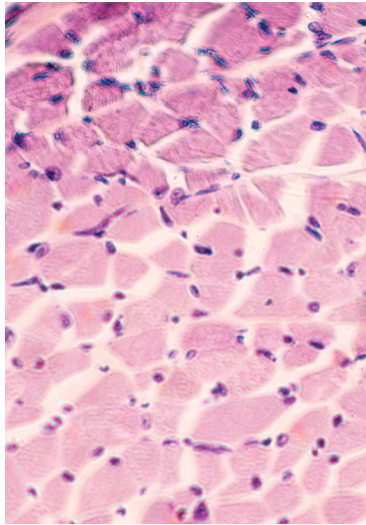
Looking after your joints and muscles may include a combination of physiotherapy access and support from your healthcare provider, postural management, passive and passive-assisted movements and the use of splints or supports (orthoses). This booklet provides information on each of these aspects, with the aim of supporting you in living a healthy and more active life.

Physiotherapy helps to keep muscles moving and slow down contractures

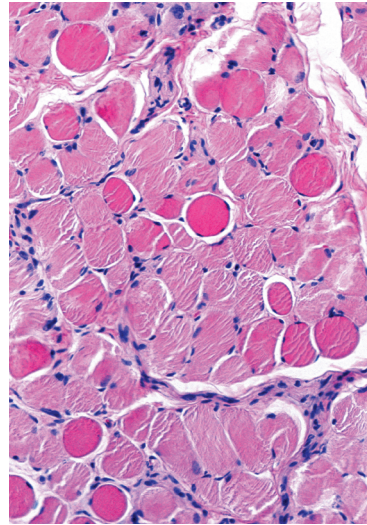
You will have heard the term “if you don’t use it, you lose it”? When it comes to muscle, this is true for everyone. Muscles will shorten with lack of use, irrespective of the presence of a muscle condition. Keeping joints as healthy as possible through movement is also an important part of your healthy lifestyle. As joint range is lost, pain can develop and many adults with DMD require some form of pain management programme. Movement can help with pain management if undertaken on a regular basis.

A contracture is a permanent shortening of a muscle. Contractures occur when the muscles are no longer able to move the joints through the full range of movement. If you are unable to take the joint to the end of the range (for example, if you cannot fully straighten the elbow, knee or hip) the muscles quickly learn that they are not needed to fully extend and lose this ability permanently.

In people with Duchenne, muscles develop contractures quickly. This is partly because muscles are weak and may not be able to straighten the joint fully. Also, as Duchenne progresses, the muscles start to exhibit fibrous (scar) tissue. This is usually an important part of the repair process to heal damaged muscle. However, as the muscle isn’t able to repair itself due to a lack of dystrophin, the repair process is always underway but never completed. This means that too much fibrous tissue develops, preventing the muscle from working properly. At the same time, damage to the muscle cells causes chronic inflammation, which prevents repair and new cell growth. This causes the muscle to become ‘tight’, affecting your movement and posture.



Healthy Muscle



Dystrophic Muscle

Whilst it may not be possible to prevent contractures, we know through case studies that people with Duchenne who undertake regular and consistent passive movements and stretches are able to maintain better posture than those who do not.

As well as helping to move our joints, muscles are integral to our immune system, bone health and maintaining insulin levels, which help control blood sugar. Keeping the muscles moving is one of the primary aims of physiotherapy in the management of Duchenne. Moving muscles regularly has an impact on health and well being in terms of boosting the immune system, helping to keep bones healthy as well as playing a part in circulation, controlling blood sugar and managing pain.

Access to physiotherapy

Ease of access to physiotherapy may differ depending on where you live; however, there are various options you may wish to explore:

- A physiotherapist who has expertise in the adult form of the condition is helpful when managing Duchenne. There are a few adult physiotherapy specialists around the country and it may be worthwhile seeing if you can access a specialist physiotherapist through the Adult North Star Network as a one-off. Muscular Dystrophy UK may be able to tell you if there is a specialist physiotherapist in an area nearby. This may mean that your doctor can write to the consultant in a different area and ask for a 'second opinion' if your local healthcare provider is willing to pay the costs. Sometimes, if there is no specialist Doctor or physiotherapist in your area, a very good case can be made for consulting with an expert in a different area
- A referral can also be made to local physical rehabilitation teams or local adult disability community teams. Whilst your local physiotherapist may not have specialist knowledge of Duchenne, they will have knowledge of 24-hour postural management, passive movements, stretches and pain management that will be relevant to your overall healthcare needs
- Some adults with Duchenne find they receive good advice from private physiotherapists who have neurological expertise, for example in motor neurone disease or multiple sclerosis. Whilst they may not be familiar with Duchenne, they will have an understanding of joint management and postural care.

Developing a complete stretching and postural management routine

Over the years you will have become used to stretching out your joints, both by yourself and with the help of a parent, carer or personal assistant at school. As you get older, the way in which you do the stretches will change as other factors in your healthcare management also become important.

Stretching is one part of the muscle and joint management routine that should become part of your everyday life. The benefits of stretching are further enhanced by good postural management in sitting and lying. Passive movements or passive assisted movements, where you move your joint through the range that you can and a carer will move it the rest of the way, should also form part of your overall management routine, as may the use of orthoses (splints).

Postural management

When you are no longer able to change position and move frequently, you are more likely to develop contractures. At this stage, it is important to access healthcare professionals who can work with you to help you achieve a good sitting posture in your wheelchair and chair at home and at your school or workplace (if it is different to your wheelchair) as well as assessing your position when you are lying down or in bed for the night. This helps to make sure your joints are maintained in a good position. Each healthcare professional has different expertise and it may be that you will require input from wheelchair services, physiotherapy, occupational therapy and District Nurses to achieve a complete postural management assessment.

If you do not have access to a postural assessment, ask your doctor if they can put you in touch with someone who can advise. You can also contact your Care Adviser or District Nurse as they too are often a good source of information.

Passive/passive-assisted movements

In addition to postural management, movement is an important part of looking after your joints and muscles. When your muscles are unable to move the joints through their full range, a physiotherapist can help you explore other ways of moving your joints. This is important to keep your joints healthy and minimise joint pain as you get older. Moving the joints means the muscles are also moving.

Passive/passive-assisted movements help to warm up the muscles prior to stretching.

Passive-assisted movement

You can do passive-assisted movement with a family member, friend, carer or personal assistant. This is when you move your joints through their full range with help.

You may be able to move your joints a little: for example, you may be able to bend and straighten your elbow in mid range but not completely straighten or bend it. The person helping you can support you and move your joint into the innermost and outermost ranges and you can help by moving it in the middle.

Passive movement

If moving is very difficult, the person helping you can move your joint the whole way for you. This is called passive movement.

During passive or passive-assisted movements it is important that the person supporting you looks after your needs as well as their own posture. A physiotherapist or moving and handling assessor can offer advice if required.

When should you do passive/passive-assisted movements?

When to do your movements is a personal choice. It takes around 20–30 minutes to complete all of your daily movements, during which each joint should be moved 25 or 30 times.

Some people choose to do their leg and arm movements before they get out of bed in the morning. This wakes up their joints and helps them get ready for being in their chair for the day. Others may prefer to do their leg movements in the morning before they get up, and their arm movements after lunch, for example. If you have a chair that tilts and reclines you may feel it is helpful to do the movements a couple of times a day with your carer when you feel stiff.

It is entirely your decision and doing even a few movements a day is better than none at all.

Carrying out movements and stretches safely

- If doing the movements on a bed, make sure you are supported with pillows under your leg. Your knee caps should be facing the ceiling and the leg should be supported in a neutral position. If you are in your wheelchair, you may choose to remove the foot support
- Ensure the person supporting you gets as close to the joint as possible. Holding the limbs at arm's length puts strain on both you and the other person
- The person helping you should use soft and open hand holds. As well as being the best way to move your joint, this will help them to preserve good posture
- The joint should be taken to the end of the range available at a continuous, steady pace
- Guide the person helping you as to how far to take each stretch, how fast or slow to perform the movements and how many times you would like your joints to be moved
- Movements and stretches should not be painful – if they are, tell the person assisting you so that they can stop

Getting the help you need

- Ensure that your caregiver is made aware of the support you require. It is important to communicate your needs around muscle and joint care when negotiating your care package with social services or your local healthcare team
- If you have a physiotherapist, they can show the person who helps you how to do the required movements and stretches

Examples of movements and stretches

The following pages contain examples of passive/passive-assisted movements with the stretch hold at the end.

At the end of each movement cycle (that is, after you have completed each passive/passive-assisted movement enough times to ensure the muscle is warm) you are ready for the stretch. The stretch hold can be done 2 /3 times during the movement cycle or alternatively can be done at the end of the movements.

Hold the stretch for as long as is comfortable, building up to 15 to 20 seconds. Repeat each stretch three times.

The Scottish Muscle Network provides videos of some of the passive movements on its website which you may find helpful to view in addition to this guide:

<https://www.smn.scot.nhs.uk/patients-and-families/education/>
(Please note that this website is an external resource and PTC is not responsible for its content or accuracy)

NOTE: These videos are only for use by patients/families who have been consulted and directed by their healthcare professional following discussion around exercise

Toes

Movement:

With the ball of the foot supported, bend the toes forwards and back

Stretch:

Reaching across the top of the foot, point the toes downwards and hold



Ankles

Movement:

1. With the leg supported at the ankle, move the toes and ankle until they are pointing away from you. Then move them back upwards until the toes are pointing to the ceiling
2. Circle ankle in both directions

Stretch:

Hold the foot upwards until a stretch is felt at the back of the ankle



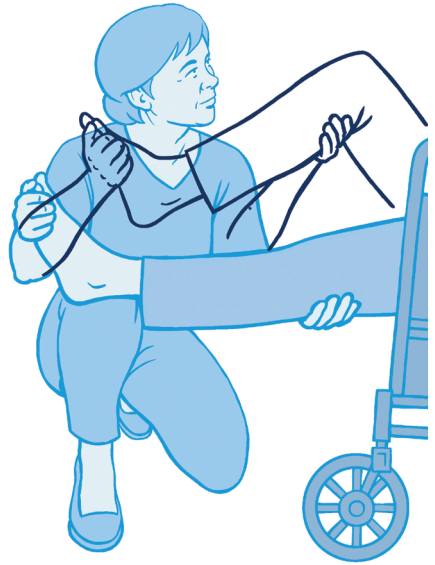
Knees

Movement:

Bend and straighten the knee

Stretch:

Hold the knee in a position where it is as straight as is comfortable



Hips

Movement:

1. Take the knee into the chest and back
2. Take the knee out to the side and back
3. Rotate the lower leg in both directions



Fingers

Movement:

Bend and straighten the fingers

Stretch:

With the wrist joint supported, extend the fingers until a stretch is felt



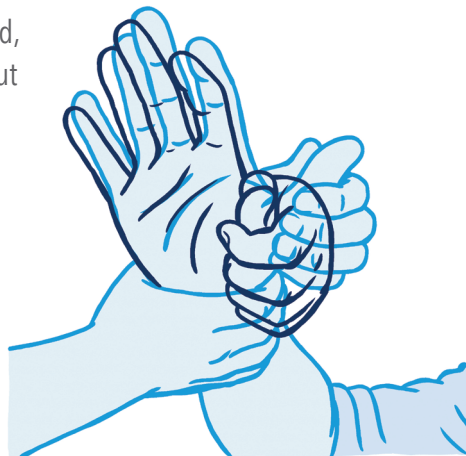
Thumb

Movement:

1. Move the thumb across the palm and back again
2. Rotate the thumb in both directions

Stretch:

With the wrist and fingers supported, gently move the thumb back and out to the side



Wrist

Movement:

1. Bend the wrist up and down
2. Move the wrist from side to side

Stretch:

Hold the wrist back by pushing on the palm of the hand whilst keeping the fingers straight



Forearm

Movement:

Hold the hand as though you are going to shake it.
Turn it palm upwards and then palm downwards

Stretch:

Turn the arm so that it is facing palm upwards and hold



Elbow

Movement:

Bend and straighten the elbow

Stretch:

Hold the elbow out straight at the end of the range of movement until a stretch is felt



Shoulder

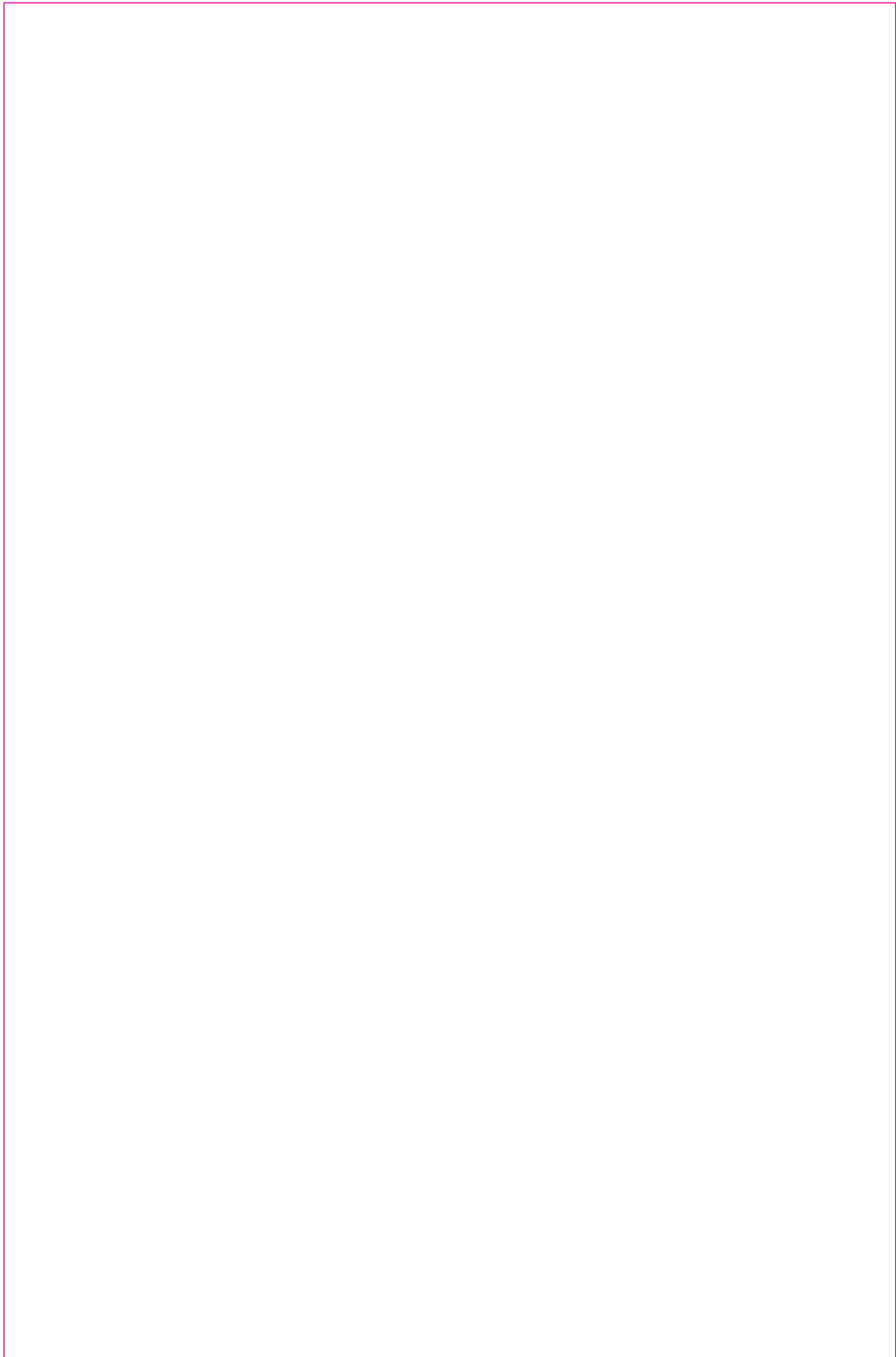
Movement:

1. Take the elbow out to the side up to shoulder level
2. Take the elbow and hand up above the head

Stretch:

Take the hand up above the head
- or as far as is comfortable - and hold





Shoulder girdle

Movement:

With one hand supporting the front of the shoulder and the other hand supporting the back of the shoulder, rotate the shoulder blade forwards and backwards



Pelvic girdle

This movement can only be done lying down and if there is no spinal fusion

Movement:

With one hand on either side of the pelvis, gently rotate it in one direction and then the other

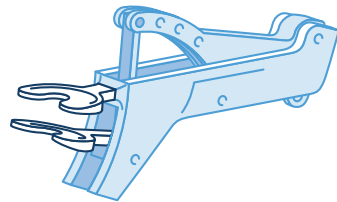


OTHER

Jaw and neck stretches

Sometimes in people with Duchenne, opening the jaw becomes more difficult as the temporal mandibular joint (jaw joint) becomes tighter. With time, this can make it harder to open and close your mouth fully, making activities such as going to the dentist and caring for your teeth more challenging. It can also make speech more difficult.

If you feel jaw opening is becoming problematic, it may be helpful to speak with a cranio-maxillofacial expert – you can usually be referred via your doctor. You may also wish to see a speech and language therapist, who can show you specific jaw stretches. However, not everyone feels comfortable with another person assisting them with these stretches. Some people find a jaw jack or therabite is useful for providing a static stretch. If movement is increased, then the width of the jack can also be increased.



Neck stiffness can also be challenging and good postural management both in bed and in your wheelchair is essential. Gentle head and neck movements, such as turning your head from side to side with help, can be useful.

Please remember: Caution is required when moving the head and neck, as this area is fragile. Let the person helping you know if you feel any discomfort during movements, so that they can stop. Always start with a small movement that can gradually be increased. If you have any concerns please discuss first with your Doctor or Healthcare Professional.

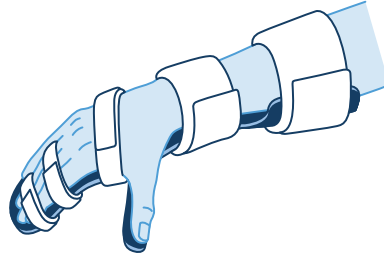


Orthoses (splints)

Orthoses can help you to maintain good positioning and perform static stretches.



Ankle-foot orthoses will hold your ankles in a good position when sitting in your wheelchair.



If your long finger flexors (the muscles that bend your fingers) are tightening, then hand orthoses that provide a static stretch can be worn for a couple of hours each day to help maintain the position of your fingers.

Even if your fingers cannot get into the position shown in the picture, wearing an orthosis is still worthwhile (if you can feel the stretch) to help maintain the length of the muscle and prevent further tightening.

Is it possible to regain lost movement?

Regaining movement that has become more difficult may be possible whilst there is still some viable muscle. It may require a more intensive programme that includes movement, passive stretches and static stretches (with orthoses).

Once the muscle becomes completely fibrotic (turns to scar tissue) it may not be possible to get back movement that has been lost. However, efforts to maintain movement through the available range may help prevent further tightening of the joint and keep the joint healthy.

Looking after your muscles and joints is an important part of staying healthy, along with taking care of your bones, breathing, heart and nutrition

As an adult, there are various options for gaining access to a physiotherapist, who can give you advice on a programme that suits your individual needs

This programme may include postural management, passive/passive-assisted movements, stretches and the use of orthoses

Maintaining good posture while sitting and sleeping, along with daily passive/passive-assisted movements and stretches can help to keep your joints healthy and minimise joint pain, helping you to live a more active life for longer