

Scottish Muscle Network

Patient Information Leaflet

An active lifestyle: What is suitable activity for people living with a muscle disorder?

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Introduction

Activity and exercise are important parts of everyone's life regardless of whether you have a muscle condition or not. Everyone has to move around each day whether we are taking informal exercise in the form of walking, going out in a wheelchair, housework or just playing with our children or friends, to participating in a formal exercise programme such as going to the gym.

When we think about activity and exercise, we often make a distinction. Activity is something we do informally, and exercise is something that is harder and involves a bit more thought and formal processing.

We often think of exercise as:

- a programme of movement that involves weights or resistance
- a physical effort that is planned, structured and repetitive
- something that we push ourselves to the limits of our fitness levels
- movement that gets us out of breath

Some people believe that exercise requires willpower, motivation, and stamina and for many people with a muscle condition, this can be overwhelming. It is not always possible to get to a gym or swimming pool. Changing rooms can be challenging and often there is a need for a carer to be present so suddenly going out to do 'a bit of exercise' becomes a major event which needs a good deal of planning.

However, exercise does not need to be formal or make you feel negative about it. We do not need to gradually increase what we are doing, lift weights or raise our heart rates to a specific level to feel the benefits. We just need to start doing a bit more than we did before by becoming more active. Suddenly the thought of doing a little bit more can feel less overwhelming. Movement is so good for us, but we often make it more daunting than it needs to be and simplifying our daily movement practice by just doing a little more will gradually start to improve, not only our physical fitness and health, but our overall wellbeing.

Activity is good for many reasons, and you can mix and match the type of activity you do to get the most from your workout. It also helps prevent boredom.

Housework, gardening, and shopping (and I don't mean online!) are all forms of activity so don't need to feel that you have to wear lycra and sweat buckets to improve your health. This is most certainly not the case. Any increase in activity will be good for you.

All you need to do is get moving and move more often!

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Let's think about different types of activity

Graded Exercise, the type of exercise that we build regularly and train hard for is not normally recommended in Neuromuscular Disorders.

This is a more formal type of exercise that regularly increases in:

- intensity (how hard you are working)
- frequency (how often you do the activity)
- duration (the length of time you work at each session)
- resistance (increasing the weight you are lifting or resistance you are using)

Graded exercise is essential for people who are undertaking competitive sports, or for those who want to develop a more formal approach to their fitness regime or are perhaps training for a specific sporting event. Doing more exercise in stages and pushing yourself harder at regular intervals is not always helpful if you have a muscle disorder. Many people with a muscle disorder just want to feel as good as they can and there are many ways to do this. Setting unrealistic goals can leave you feeling fed up with yourself and then you end up doing nothing. You can speak to your physiotherapist about your current level of ability and work together to find the best way forward. In some circumstances, your physiotherapist may suggest specific graded exercise, but this is usually within a rehabilitation setting and needs to be monitored in certain types of muscle conditions.

Benefits of activity

Activity is good for us, and everyone has a different level of fitness, stamina and resting muscle strength. We all have our likes and dislikes too so you can decide what activities you want to do as if you enjoy it, it's more likely to be something you will do on a regular basis.

Most people believe that when they are active, they feel better and indeed there is a lot of research to support this. Activity can raise your mood and help your confidence and self-esteem. If your activity is out of doors, you will get Vitamin D from daylight which will improve your overall well-being.

Increasing activity will also help improve your sleep and will boost your energy levels. Even if you have a progressive muscle disorder, keeping active is important to prevent disuse atrophy, (muscle wasting caused by a lack of movement) and deconditioning.

Deconditioning syndrome

Deconditioning syndrome can affect anyone who is inactive or suddenly becomes less able to move around. It can happen if you have an accident and are off your feet, if you have flu and end up on bed rest for a few days or for any reason that causes you to reduce your activity levels. Many people will feel a bit unfit but will gradually build their stamina and fitness back up to where it was before.

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However, in muscle conditions, weakness is inevitable, but the weakness will cause more issues if you become deconditioned. In deconditioning syndrome, we see a loss of muscle definition, loss of strength, deterioration in the speed of nerve impulses moving along the nerve as well as a deterioration in the way the impulse is transmitted across the neuromuscular junction. The muscle contraction becomes less effective, and it feels everything is so much harder. This causes us to move less, and the deconditioning continues to progress.

The good news is that this is reversible and once we start to move around more and become more active, our muscles will respond by becoming more effective and efficient and you will feel stronger, have more energy and notice improvements in your mood and immune system.

If you are overweight, activity can help burn more calories by maintaining muscle as much as possible and if you are already eating a healthy, wholefoods, balanced diet, can help maintain or reduce weight. If you have concerns regarding your weight, a dietitian can give you more advice.

What else is becoming more active good for?

Being active also improves the circulation. When the heart rate is increased, blood is pumped around the body faster to make sure the muscles are receiving the oxygen and nutrients they need. Being active also works our heart muscle and having good heart rate variability is becoming more talked about around health and wellness. Heart rate variability (HRV) is the fluctuation in the time intervals between adjacent heartbeats and healthy HRV means we have good physical and mental resilience, healthy stress management and general cardiac well-being. A healthy heart will have good HRV as it responds to the demands of exercise and activity as well as being able to slow down when resting. Good HRV helps regulate blood pressure and can be an indication of our overall health. Being active helps achieve healthy HRV.

Activity helps our lymphatic circulation too. We often don't think too much (or at all) about the lymphatic system but maintaining good lymphatic flow is an important consideration. Our lymphatic circulation works much better when we are active as unlike our blood vessels, it doesn't have the heart pumping the circulation through our lymph vessels to the same extent. Activity increases muscle contraction and the more muscles that work, the better our lymphatic system will be. The lymphatic system is directly linked to our immune system and is responsible for clearing out all waste products, old and diseased cells and generally removing toxins from our body via the bloodstream. The lymphatic system also helps the body regulate fluids and absorb fats. It is a very hard-working system and is dependent on activity to keep it functioning optimally.

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Types of activity

There are three main types of activity that are primarily recommended in muscle conditions:

1. Stretches
2. Aerobic Activity
3. Anaerobic Activity
4. Passive Movements

1. Stretches

Stretching can help pain caused by tight structures and can also help improve your balance and coordination. Stretching can improve your circulation by maintaining good artery function and maintaining good blood pressure levels. It can help maintain your independence when doing everyday activities. As muscles tighten, range of movement is lost, and this can make it more difficult to fasten zips and buttons and attend to personal hygiene such as bathing. Maintaining the elasticity of the muscle will help prevent contractures (tightening of the muscle so the joint is no longer able to move through its full range of movement).

Stretches are more beneficial when the muscles are warm so after a bath or an activity are good times to get the most out of your stretches. It is important especially to stretch if you are not independently able to put your joint through the full range of movement, every day. If you feel tight or are losing range of movement in any joint, then starting to stretch that joint can help.

Your physiotherapist can advise on the best stretch for that joint but generally, the stretch should be held for around 20 to 30 seconds and repeated three times. You should hold the stretch steady, and it is important that you feel the stretch. If you don't feel the stretch in the muscle, then you are not stretching enough. However, it is important that the stretch does not cause pain. For more information on your daily stretching practice, please refer to the ["Benefits of stretching booklet"](#)

2. Aerobic activity

This type of activity includes cycling, swimming, walking, propelling your wheelchair and even going out in your powered wheelchair. When taking part in aerobic activity, you will breathe faster and more deeply. This increases the amount of oxygen in your blood. Your heart will beat faster, which increases blood flow to your muscles and back to your lungs. Your small blood vessels (capillaries) will widen to deliver more oxygen to your muscles and carry away waste products, such as carbon dioxide and lactic acid. Your body will release endorphins, natural painkillers that promote an increased sense of well-being.

Our muscles will also release proteins called myokines into our blood stream. Myokines have been shown to boost our immune system, help strengthen our bones

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and lift our mood. Our bodies are truly amazing particularly when we learn to listen and work with our body harmonising our physical mental and emotional well-being.

However, it is important to remember that in neuromuscular disorders, your muscles will tire more easily so it is essential that you do what you feel able to do. If you overdo things, you are more likely to have a strain, or a sprain so take it easy and gradually learn what your body can do safely as this can change on a day-to-day basis. Some days you will be able to do more than others, and this is okay. Always work within your energy and fatigue levels. Your physiotherapist can advise on appropriate activities.

3. Anaerobic activity

This type of activity relates to weights and resistance training. Although we would not always recommend this type of activity, it may help some people. In certain neuromuscular disorders, resistance training or repeatedly lifting weights can stress the muscle cell which is not recommended for conditions such as Duchenne Muscular Dystrophy as this can cause the muscles to weaken more quickly. If there is proximal weakness (weakness of the body, shoulders and hips), lifting weights or undertaking resistance can put more strain on the shoulder and hip joints and may cause short- or long-term damage. Your physiotherapist can advise further on this.

Strength training is a good activity for some people and is to be encouraged in conditions such as Charcot Marie Tooth disorder for example and this is an area where graded exercise within limits would be appropriate. However, it is important to be aware of your own fatigue levels and change your workout, if necessary, as fatigue can vary from day to day.

When we stand up, climb stairs, transfer from our wheelchair, or lift and carry shopping, we are undertaking strength training as working against gravity is a form of resistance. This resistance is important to maintain our muscle strength. We all have a specific resting muscle strength where we don't use all our muscle fibres. When we start to use our muscles a bit more, we begin to use more muscle fibres and our muscles become more efficient. Despite the fact we have not "grown" any more muscle fibres, we feel stronger because our muscles are working more effectively. This is an important part of keeping fit and healthy.

When our muscles are working more efficiently, they support our joints more efficiently and our posture improves. We are less likely to develop pain caused by poor postures. (See the supporting information leaflet on postural management).

Lack of exercise can cause muscle loss (if you don't use it, you lose it) and when muscles weaken, you are more likely to develop osteoporosis (brittle bones). This is because the muscles are exerting less of a pull on the bones which in turn means the bones don't need to be as strong therefore osteoporosis develops. As discussed earlier, when our muscles move, they release proteins called myokines which boost our bone growth and our immune system as well as having a positive impact on many other body systems. In addition, a good diet and maintaining muscle strength is a good way to help keep bones healthy.

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4. Passive movements

These are movements that are carried out with the assistance of someone else and are performed in a rhythmical and smooth manner through the available range of motion. The movements are done within the same range and direction as active movements. The joint is moved through the free range and within the limits of pain.

Passive movements can maintain the range of motion and help prevent muscle tightness by preserving the physiological properties of the muscle (extensibility, elasticity, etc.) as well as preventing contractures (shortening of the muscle). When you do these movements regularly, they help preserve the memory of the movement pattern within the muscle itself as well as the movement pattern in the brain which is good for our proprioception i.e. knowing where our body is in space without needing to look. This is good for our balance and helps us interact with the world around us especially when out of doors. If you are not able to actively move your joints through a full range of movement, you probably need some help. Your physiotherapist can teach your carer / PA, partner, or family to help you with some movements. This should not take up more time than 20 minutes at any one time. You should aim to do these movements as often as possible and certainly aim for a daily routine, to help with pain, circulation, and tightness. Passive movements will keep your joints healthy and if you are able to join in with the movement, even if it is only for part of the movement, using your muscles to help the movement, will make it even more beneficial.

There is a video on the Scottish Muscle Network website that demonstrates passive movements within a wheelchair. You will find this video in this section.

<https://www.smn.scot.nhs.uk/podcast-and-videos/passive-movement-videos/>

If you are wheelchair dependent, movement through all the planes (up and down, back, and forward and side to side) is especially important to help maintain your spatial awareness. When sitting all day, you are viewing the world from one perspective, and it is easy to lose your ability to judge spaces, speed and distance. Moving your joints through different ranges helps maintain your sense of “space”. Your physiotherapist will tailor a programme of passive or passive–assisted movements to suit you. If you notice any change in your condition, you can change this programme so that it always helps you be as active as possible. If you are particularly tired on one day, then you can leave it until the next. Always remember that you are in control of any activity you do and only you know how you feel on that day.

Conclusion

Activity is one of the most important things we can do to help our overall health. It is not always easy to know where to start, what type or how much to do. Your neuromuscular physiotherapist can help with this and work with you, your carers, and your family to help you get the most out of your activity practice. Finding something you enjoy is the key to maintaining the activity and once you start to enjoy the health and social benefits of your more active lifestyle, you will wonder why you waited so long!

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Further Information

For more information on an active lifestyle in neuromuscular disorders, please contact your physiotherapist.