Acute Services Division

NHS
Greater Glasgow and Clyde

Supporting information leaflet (5):

Stretches and Activity (Exercise) for people with Neuromuscular Disorders

Introduction

Exercise is an important part of all of our daily lives. 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.

Exercise is often:

- 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
- an activity 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 in order to feel the benefits. **We just need to start doing a bit more than we did before by becoming more active.**

Activity is good for many reasons and you can mix and match the type of activity you do in order to get the most from your workout. Housework, gardening and shopping (and I don't mean online!) are forms of activity so you don't need to feel that you have to wear lycra and sweat buckets to improve your health.

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

Graded Exercise is not normally recommended in Neuromuscular Disorders. It 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. Doing more exercise in stages and pushing yourself harder at regular intervals is not always helpful if you have a neuromuscular disorder. Many people with a muscle condition just want to feel as good as they can and graded exercise is not usually the best way 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 exceptional circumstances, your physiotherapist may suggest graded exercise but this is usually within a rehabilitation setting and not generally for everyday fitness.

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 sunlight 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 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.

In muscle conditions, weakness is inevitable however the weakness will be more damaging 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 and if you are eating sensibly, can help maintain or reduce weight. A Dietitian can give you more advice.

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.

Types of Activity

There are three main types of activity:

1. stretches
2. aerobic or anaerobic activity
3. 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 lowering the blood pressure. 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 (www.smn.scot.nhs.uk/physiotherapy)

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 then release endorphins, natural painkillers that promote an increased sense of well-being.

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

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. Although, it is important to be aware of your own fatigue levels and change your workout if necessary.

When we stand up, climb stairs, transfer from our wheelchair or lift and carry shopping, we are undertaking strength training as 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 of 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 better 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.

3. 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 propriioception 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, partner or family to help you with some movements. This should not take up more time than 20 minutes. 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 the physiotherapy section. (https://www.smn.scot.nhs.uk/professionals/physiotherapy/)

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 particular 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 planned workout. 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!

For further information

For more information on an active lifestyle in neuromuscular disorders, please contact Marina Di Marco, Principal Neuromuscular Physiotherapist (marina.dimarco@ggc.scot.nhs.uk) or 0141 354 9205).

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