

Exercise advice for adults with muscle-wasting conditions

Introduction

It's official: exercise and physical activity are good for you. It can also be a lot of fun and help you to widen your social contacts. In May 2010, the Department of Health published guidelines – based on scientific evidence – for physical activity in the general population. The research showed that regular physical activity and exercise reduce the risk of many common diseases, such as heart disease, type II diabetes and certain cancers. It also showed that it is important for improving long-term health and wellbeing.

General health benefits of exercise

- Reduces the risk of other diseases (e.g. heart disease) and promotes a healthy lifestyle.
- May improve or maintain your ability to perform everyday tasks.
- Reduces fatigue.
- Can improve bone density.
- Assists in controlling your weight.
- Improves your mood.
- Can improve your sleep.

So everyone can benefit! Having a muscle-wasting condition does not exclude you from participating in exercise. In fact, we now understand that exercise is important and can help improve your fitness, your ability to carry out day-to-day tasks, and it can also make you feel good. Knowing where to start, however, or what exercise to do, can be daunting.

It is important to remember that 'exercising' does not mean you have to go to a gym or to a formal exercise class. Simply increasing how much you move around or being more physically active during the day can be just as important. Exercise can be focused on addressing a specific problem, or it can be more general to keep you fitter and healthier. The type of exercise that will suit you best will depend on your own specific needs and interests.

You can help yourself to feel better and do more through regular exercise – and the information in this leaflet can help you to make a start. This advice is aimed at adults, and because each person with a muscle-wasting condition is different, it contains the general principles of exercising rather than specific exercises. If you have not done any exercise for a while, the key is to start slowly and gradually build up. If you are already exercising, the information here may help ensure you are doing the correct type of exercise in the most beneficial way.

Talk to your doctor or physiotherapist about exercise before you start especially if you are still undergoing diagnosis or having heart investigations.

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Benefits of exercise in muscle-wasting conditions

Although the precise amount and type of exercise for people with muscle-wasting conditions has not been fully established, it is now widely agreed that moderate-intensity aerobic exercise or physical activity (*exercise which increases your heart rate and rate of breathing while still being able to talk*), and low- to moderate-strength training has the potential to improve general fitness.

Although exercise is thought to be good for everyone, the type and level of exercise will depend on your specific muscle-wasting condition and your current level of physical ability.

The right kinds of regular exercise can reverse some negative effects of being inactive (or *de-conditioned*).

Inactivity in people with muscle-wasting conditions can lead to:

- further loss of muscle bulk
- reduced stamina
- increased levels of tiredness
- muscle and joint pain
- weight gain
- decreased bone density.

Exercise can also help with specific issues associated with muscle-wasting conditions, as well as providing the general health benefits described earlier.

Benefits of exercise, specifically for those with muscle-wasting conditions:

- it helps make the most of your good (unaffected) muscles
- it improves heart and lung function
- it can prevent or reverse physical de-conditioning (maintain stamina/endurance)
- it can reduce pain
- it helps maintain or improve joint range of movement
- it can prolong your ability to perform functional activities, such as walking and climbing stairs.

Common questions

Will exercise help me?

As stated above, exercise or an increase in physical activity is good for everyone, but we know that each person with a muscle-wasting condition is different and you will need an exercise programme tailored to your own requirements. To help you and your physiotherapist develop an appropriate exercise regime, and progress it, we have

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described 'exercise' as a 'medicine', i.e. what exercise you should consider taking, how much and how often. Here is an explanation of some terms you might come across.

Mode	The types of exercise, e.g. aerobic, strengthening, balance.
Frequency	How often you should exercise, e.g. the number of times a day or week.
Duration	The length of time spent exercising, e.g. per exercise, per session.
Intensity	How hard should you be working.
Precautions	Condition-specific cautions; some muscle-wasting conditions may respond differently to exercise.
Progression	As changes occur, the exercise 'prescription' may need to be altered.

What type of exercise should I do?

There are several different types of exercise which can be beneficial for you. However, it is important to find an activity you enjoy doing as this will encourage you to exercise regularly. In this leaflet, we concentrate on three main types of exercise: aerobic, strengthening and stretching.

1. Aerobic exercise

This type of exercise is any activity that raises your pulse and/or rate of breathing. It uses large groups of muscles and can usually be sustained comfortably for a number of minutes. Examples of aerobic exercise are walking, swimming, using an exercise bike, propelling your wheelchair and even doing housework. These types of exercises improve the function of your heart, circulation and lungs, and by improving your general fitness, they are also good for your overall health. Discuss with your physiotherapist what type of aerobic exercise may be best for you.

How often should I do aerobic exercise and how long should each exercise session last?

Ideally, for general health benefits you want to try to do aerobic exercise at least five times a week, building up to an exercise session which is 30 minutes long (i.e. a total of 150 minutes per week). However, you should aim to be active every day.

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Like many people with muscle-wasting conditions, you may find that doing 30 minutes of exercise in one go is difficult at first, owing to muscle tiredness and general fatigue. You don't need to do it all in one go; for example you could break the half hour into three 10-minute sessions.

If you aim to do 10-minute blocks of exercise or physical activity, that's great! However, remember **something is better than nothing**: even relatively small increases in physical activity can protect you against chronic disease and can improve your quality of life.

When you start exercising, make sure you include rest periods and then over the next few sessions/weeks, you can gradually start to increase the length of each session. For some people with muscle-wasting conditions, it may be better not to do long exercise sessions on consecutive days (over and above your day-to-day tasks), so you can allow time for your muscles to recover. It's a good idea, therefore, to spread your exercise sessions across the week. This may not always fit in with your lifestyle or other commitments, however frequently exercising above the recommended dose on consecutive days may lead to increased fatigue.

How hard should I exercise?

Aerobic exercise does not need to be strenuous, however exercise of 'moderate' intensity is recommended to achieve changes in aerobic fitness and improve your general health.

When you do aerobic exercise, you should feel comfortably out-of-breath (breathing a little faster) but still be able to talk. The exercise should also make you feel warmer and make you perspire a bit.

A good way to establish your exercise intensity is to use a commonly used scale called the 'Borg Scale'. We encourage people with muscle-wasting conditions to work at Borg levels 3-5 if you can.

0	Nothing at all
1	Very light
2	Fairly light
3	Moderate
4	Somewhat hard
5	Hard
6	
7	Very hard
8	
9	
10	Very, very hard

Borg RPE scale © Gunnar Borg, 1970, 1985, 1994, 1998

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You can also determine your exercise intensity by wearing a heart-rate or activity monitor. You may wish to discuss this with your physiotherapist, who can also help you set training/heart-rate targets if you wish to do so.

Each longer exercise session should also include a three to five minute warm-up to increase your body temperature and reduce the potential for post-exercise stiffness, and a five to ten minute cool-down to allow recovery of your heart-rate. Your therapist can help you decide how you do this.

2. Strengthening exercises (resistance exercises)

These exercises can include lifting small weights or pulling elastic exercise bands. It is best to talk to your physiotherapist about which muscles you should strengthen and how, as this will be different for everyone. For some types of muscle-wasting conditions, this type of exercise is not advised, so please seek advice at your next review appointment or contact your medical team before proceeding.

Generally, strengthening exercise programmes involve the major muscle groups. It may not be possible to strengthen very weak muscles or muscles which are very wasted. If the muscles around your shoulders or hips (proximal muscles) are affected, you will have to take extra care; talk to your physiotherapist about the most appropriate exercise for you.

A muscle will lose strength if you stop exercising it. This is called 'disuse atrophy' – in other words, if you don't use it, you lose it. However, it may be more important to think about improving the endurance of your muscles, rather than strengthening or trying to build up muscle bulk. This is more important for day-to-day tasks and will allow you to perform tasks for longer, for example, being able to climb more stairs before you get tired.

Remember, it is important not just to think about strengthening the muscles of your arms and legs; strengthening your stomach and back ('core') muscles is also very important. Improved core strength can help improve your posture and balance, and help with functional tasks such as wheelchair transfers. It may also reduce the risk of falls.

How often should I do strengthening exercises and how long should each exercise session last?

You should try to perform strength exercises two or three times a week, and you should consider the time you spend doing strength exercises *in addition to* the amount of time you spend doing aerobic exercise.

You can vary the length of each session depending on how many muscle groups you are exercising and how many repetitions and sets you do.

How hard should the strengthening exercises be?

We advise that low- to moderate-strength (resistance) exercises are safe for many people with muscle-wasting conditions. This view is supported by research, however the lifting of very heavy weights is not advised. It is generally thought that increasing the number of repetitions is better for you than increasing the weight you lift. For example, if your muscles are not tired after lifting a weight 8 times, try lifting it 10 times.

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At the end of your exercise session, you should still be able to maintain the correct position of the exercise. Don't overdo it, and stop the exercise if the muscles shake too much or the movements become jerky.

It is better not to do strength exercises on consecutive days; give your muscles a chance to recover. Also, within an exercise session you should alternate the muscles you exercise, so if you start with an arm exercise, then do a leg exercise next.

When you start a new strength exercise you might expect to be a little bit achy, but any muscle soreness should have gone after 48 hours.

3. Stretching exercises

Flexibility and having a good range of movement in your joints is important for day-to-day activities, therefore stretching exercises are good to include in your exercise programme. They can make tasks such as bathing and dressing easier and they can also help to improve your balance and muscle function.

If any particular muscles or joints are stiff, you may need a more focused stretching programme. Please take care that you do not over-stretch weak muscles or joints that are already very mobile. Speak to your physiotherapist, who can advise you which muscles or joints it would be good for you to stretch.

It is easier and safer to do your stretches when your muscles and joints are warm, so good times to do these exercises would be after you have been active, towards the end of the day or after you have had a bath.

While there are no specific stretching regimes recommended for people with muscle-wasting conditions, activities such as gentle yoga can be rewarding and effective.

How often should I do stretches and how long should each exercise session last?

Stretches are more effective if they are done regularly. If you can include them in daily tasks, such as doing stretches for your calf muscles while brushing your teeth, it is a good way to save time and a regular reminder to do the exercise!

The length of time you need to 'hold' a stretch will depend on the joint or muscle you are stretching. Your physiotherapist will advise you about this; usually 30 to 60 seconds is recommended. It is important not to 'bounce' when you stretch, instead the stretch should be slow and sustained.

General questions about exercise

Where should I exercise?

Exercise doesn't have to be done in a gym. Doing exercise at home or using your journey to work are equally as effective. It is a personal choice and it is important to choose an environment or setting that suits you and that you will enjoy.

How can I progress my exercises?

Progress and build up your activity levels gradually, particularly if you are currently not very active. You can improve your fitness and general wellbeing through exercise, but it's

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important that you do this safely; your physiotherapist or other professionals involved in your care (fitness or gym instructor) can advise you on this.

Remember that maintaining your current level of physical ability is a good outcome; it's not necessary to see big changes from your new exercise regime to know that it's working.

How do I keep motivated?

The best way to keep motivated is to do something you enjoy. Some people find keeping a diary of their exercise, exercising with a friend or using a pedometer (which tracks how many steps you take) help to keep up motivation and enjoyment.

Can exercise do me harm?

Rarely does exercise do any harm, but there are a couple of considerations in particular types of muscle-wasting conditions where more caution may be needed. Your physiotherapist or medical team can advise you on this.

TYPE OF EXERCISE	FREQUENCY	INTENSITY	DURATION	PRECAUTIONS
<p>Aerobic exercise <i>E.g. walking to work, wheeling your wheelchair, activities of daily living, cycling, swimming or static bike</i></p> <p>Any activity that uses large muscle groups and can be maintained continuously and rhythmically for a period of time</p>	<p>Try and make being active part of your daily routine or try to be active in these ways at least five times a week</p>	<p>Comfortably out of breath but still able to talk</p> <p>Borg scale 3 to 5</p>	<p>30 minutes, or intermittent bouts aiming for at least 10 minutes</p>	<p>Do not exercise to exhaustion</p>
<p>Strengthening exercises <i>E.g. exercise bands, small weights or Pilates</i></p> <p>Individual programme: seek advice about which muscles you should strengthen</p>	<p>Two to three times a week</p>	<p>Stop before fatigue</p>	<p>One set of 8 to 12 repetitions for each muscle group identified</p>	<p>Low to moderate weights</p> <p>Increase number of repetitions rather than weight</p>
<p>Flexibility <i>E.g. stretches (seated or standing), yoga</i></p> <p>Static or passive stretch</p>	<p>Try to do this as part of your daily routine or at least</p> <p>Two to three times a week</p>	<p>Stretching sensation but not pain*</p>	<p>30 to 60 seconds</p> <p>Two to four times</p>	<p>Do not 'bounce'</p> <p>No pain</p>

***Take extra care with any of the above if you have altered sensation, very weak muscles or poor balance.**

Summary

Before you start exercising:

1. discuss your plans to start exercising with your medical team
2. discuss your plans with your GP who will advise you if you have other health concerns that are not associated with your condition.

Top tips for exercising

Getting started

- Choose an exercise or activity that you enjoy. You might want to have a friend or relative with you the first time you try something new.
- Choose something that can fit into your day-to-day life and that is appropriate to your needs. For example, if you have problems with your balance it may be better to use a static exercise bike from which you can easily get on and off. Remember activities like housework or walking to work are also all good exercise.
- Start slowly with any new exercise or physical activity; know your limits.
- Exercise in short sessions and build up gradually.

Planning your exercise

- Include a warm-up and cool-down period before more strenuous exercise. This will help to reduce injury and stop muscles feeling stiff afterwards.
- 'Mix and match' your exercises to let your muscles recover and have periods of rest. For example if you have done a lot of walking (aerobic exercise using your legs), you may want your next exercise session to be strengthening exercises focusing on your arm and stomach muscles.

Intensity of exercise

- With aerobic exercise (e.g. walking) you should feel comfortably out of breath but still be able to talk, and the exercise should make you perspire.
- With new strengthening exercises, you're likely to feel a little bit achy but muscle soreness should have gone after 48 hours.

Precautions

- **Do not exercise to exhaustion.** Recognise when it is time to stop. 'Pace' your activities and take into consideration what other things you may be doing for the rest of the day/week – little and often is the key. You should not experience next-day tiredness and fatigue as you will need energy for essential tasks you need to do.
- **Avoid excessive eccentric activity.** This means avoiding repetitive tasks or exercises where the muscle is being lengthened, for example squats, or the lowering phase of a biceps curl. Eccentric exercises put much greater

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force through the muscle and can lead to more muscle soreness and potentially some damage. Your physiotherapist can help you decide which types of exercise you should focus on.

- **Be aware of 'over-work weakness'**. Sometimes muscle 'tiredness' can be confused with muscle 'weakness', but muscle tiredness should improve after you have rested. If you still feel weak after you have rested properly, then you may have done a bit too much exercise and you'll need to cut down the amount you were doing. It may be helpful to discuss this with your physiotherapist. (Remember, when you are tired you may feel your balance is not as good so take care not to fall.)
- **Exercises should not be painful.** Muscle soreness is all right when you first start a new exercise programme but it should last no longer than 48 hours. If muscle pain continues, or you experience unusual symptoms, you should stop exercising and seek advice from your physiotherapist or GP.
- Remember to protect your joints when you exercise by making sure you are in the correct position/posture. It may be best to wear your splints (orthotics) to help stabilise your joints for some exercises, especially if your muscles are weak or you have problems with your sensation. Your physiotherapist can help advise you about this.
- If you have a muscle condition, be aware if there are any changes to the colour of your urine after you have done strenuous exercise. Black or 'coca cola' coloured urine can be a sign of muscle damage (myoglobinuria) if you have exercised too hard. You must contact your medical team if this occurs.
- If you are not seen in a specialist neuromuscular service, ask your GP to refer you as it is important for your long-term care and wellbeing.



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Useful contacts and websites

Muscular Dystrophy Campaign – www.muscular-dystrophy.org

GP Exercise Referral Programme - www.gpexercisereferral.ie

English Federation of Disability Sport - www.efds.co.uk

Sportability - www.sportability.org.uk

Parasport - www.parasport.org.uk

Sport England - www.sportengland.org/our-work/disability

Sport Wales - www.disabilitysportwales.com

Scottish Disability Sport - www.scottishdisabilitysport.com

Disability Sports Northern Ireland - www.dsni.co.uk

The NeuroMuscular Centre - <http://www.nmcentre.com/>

NMC Midlands - <http://nmc-midlands.co.uk/>

Condition-specific sites where more exercise or activity information and recommendations can be found:

CMT Association - www.cmt.org.uk

Muscular Dystrophy Association (USA) - www.mda.org

AGSD-UK - www.agsd.org.uk

FSH Society (USA) - www.fshsociety.org

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Here for you

The friendly staff in the care and support team at the Muscular Dystrophy Campaign's London office are available on **0800 652 6352** or **info@muscular-dystrophy.org** from **8.30am to 6pm Monday to Friday** to offer free information and emotional support.

If they can't help you, they are more than happy to signpost you to specialist services close to you, or to other people who can help.

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