



A Patient's Guide to Exercise and Stretching

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Exercise and stretching

Stretching and exercise play a very important part in managing CMT and helping to prevent or ease the complications of the condition.

Exercise

So should people with CMT exercise? Yes, because exercise is more important for people with CMT than for friends and family without the condition.

The benefits include:

- exercise, combined with a healthy diet, is the main way of controlling body weight, which is important as being overweight or obese puts extra pressure on already weakened muscles and joints
- exercise is a great way of tackling fatigue – by exercising regularly you will find you are able to carry on your day-to-day tasks without getting so tired
- muscles are prone to becoming weak without use, making it harder to get around – exercise keeps muscles strong
- exercise helps with balance and posture.

There is no universal rule of thumb about which exercises or activities will suit you. Do not let your worries about your CMT restrict you from trying different things. Just bear the following points in mind.

- If you are doing something that causes you any pain, stop immediately.
- Get to know your own limitations and understand the difference between getting naturally tired from exercise (a good thing) and excessive fatigue (a bad thing).
- See your physiotherapist or your gym instructor and talk to them about what would suit you.
- If one exercise does not suit you, try another (eg if walking doesn't work, try cycling).

Which one for me?

Exercise does not mean you have to go to the gym. You can achieve aerobic benefits from changes to your daily routine, such as walking a bit further or climbing the stairs instead of taking the lift or standing on the escalator.

The key to getting the right amount of daily exercise is to make physical activity part of your normal routine. For example, getting off the bus one stop early, walking up the last flight of stairs, cycling to the station, walking to the shops or school are all good ways of reaching the 30 minute daily minimum.

A good form of exercise is ‘aerobic’ exercise that works your heart and lungs, for example, walking, swimming and cycling. All of these help to increase endurance, reduce fatigue, improve mood and increase your ability to do day-to-day activities.

To help with your sense of balance, exercise that strengthens your posture muscles is important, for example, yoga, Pilates and Tai Chi. These forms of exercise will also train your balance responses.

Stretching

If you have CMT, then daily stretches are vital in order for you to keep flexible in your hands and ankles. They are a vital way of helping to prevent your muscles tightening and shortening, which can lead to loss of movement and pain and deformity in your joints, particularly in the hands, feet and ankles.

Hands

In the hands, the small muscles in the palm weaken first. Over time the bigger muscles in the forearm take over hand movements, allowing you to continue with day to day tasks. The result is that the large forearm muscles overpower the smaller hand muscles setting up an imbalance. Eventually, this imbalance can be observed in the resulting flat palm, flattened knuckles and bent fingers.

Due to the number of joints, the human hand has the ability to make complex movements. But, if some of those joints become stiff, you are likely to find that you lose the ability to do everyday manipulation tasks. In CMT, weakness of the hands makes doing everyday tasks more difficult. This becomes doubly difficult if the joints stiffen up as well. Daily stretching will ensure that the joints remain supple and slow down the development of hand deformities. It is important that you get into the habit of doing these stretches BEFORE deformity and stiffness develops.

Ankles

In the lower leg, the muscles on the shin (front of your lower legs) pull the foot and toes up, whereas the calf muscles (back of your lower legs) point the toes. The calf muscles attach onto the heel bone via the Achilles tendon (at the very back of your ankle).

In CMT the muscles on the shin tend to get weaker first which results in a ‘drop foot’. The stronger calf muscles overpower the weaker shin muscles setting up an imbalance between the two. Because of this the calf muscle will gradually get shorter and stiffer, as will the Achilles tendon, further increasing the foot drop. Because the ankle needs to be at a right angle for the

toes to clear the floor when walking, the result is an increased chance of tripping when walking, increased difficulty getting the heel to the floor and a greater chance of sprained ankles.

Stretching the calf daily is something that **everybody** with CMT should get into the habit of doing to keep the calf muscles lengthened and slow down the development of the deformity.ⁱ These stretches are easy to perform and can be incorporated into your daily routine, for example during your morning shower when your muscles are warm and relaxed (just be careful not to slip) or standing up to a work surface while waiting for the kettle to boil.

Orthoses and stretching

Orthoses can play an important role in helping to maintain flexibility, joint range and prevent the muscles tightening and shortening. This can be by means of insoles which may be thicker on the outside of the foot than the inside so the foot is stretched when weight is put on it. If stretching is particularly difficult, night splints are sometimes used to stretch the calf by pulling toes up and strapping the heel down and at the same time holding the ankle straight. Similar orthoses used through the day can provide a very effective stretch as well as holding the foot in the best position for walking.

Daily stretches and exercises for people with CMT

Remember that these exercises are only a general guide. It is strongly recommended that you consult a physiotherapist to put together an exercise programme tailored to your individual needs.

If you experience any pain or difficulty doing these exercises, stop immediately and seek advice from your family doctor or physiotherapist.

Stretches

1. Calf stretch:
 - With finger tips hold onto a wall or work surface.
 - Keep your head up and back straight.
 - Place one foot forward and one foot back with the back foot and heel fully on the floor. Make sure your toes are pointing forward.
 - Let your front knee bend but keep your back knee straight.
 - You should feel a stretch in the calf.
 - Hold still for 20 to 30 seconds. Repeat three times and then swap legs.

2. Lower calf stretch:
 - Get in the same position as above.
 - Step your back leg forward so the toes are in line with the heel of the other foot.
 - Letting both knees bend, sink down with your weight on your back leg.
 - The stretch will not be as strong as with exercise 1.



- Hold still for 20 to 30 seconds. Repeat three times and then swap legs.

3. Hip stretch:

- Sit on the end of your bed with your feet on the floor.
- Lie back, keeping your legs over the edge and feet on the floor.
- Lift one leg and hug the knee to the chest.
- Hold still for 20 to 30 seconds. Repeat three times and then swap legs.
- Do not continue with this exercise if you experience back pain.



4. Hand stretch:

- Sit up to a table and place both hands on top.
- Keeping the fingers straight, bend forward at the knuckles.
- You may use your other hand to help but don't force the position. You should feel a stretch, NOT pain.
- Hold for 20 to 30 seconds. Repeat three times and then swap hands.



5. Finger stretch:

- Keeping you knuckles bent forward, use your other hand to straighten the ends of your fingers.
- It is VERY important that you avoid bending the knuckles back when stretching the fingers.
- Hold for 20 to 30 seconds. Repeat three times and then swap hands.



Exercises for posture

6. Standing posture:

- Stand with your back against a wall. Make sure the back of your shoulders and head are against the wall.
- Hold this position and then slowly slide the back of your head up the wall to stretch the back of the neck.
- Repeat the movement 10 times.

7. Sitting posture:

- Sit on the edge of a firm chair. Look straight ahead.
- Slowly sit up as straight as possible then slowly slouch down.
- Repeat the movement 10 times.
- A good sitting posture is the middle position between these two movements.



Strengthening exercises

8. Upper legs:

- Sit on the edge of your bed or a dining chair.
- Keep feet hip width apart. Keep your arms by your side.
- Stand up fully then slowly sit down.
- Repeat the movement 10 times.



9. Trunk and hip:

- Lie on your back with your knees bent and feet firmly on the floor.
- Lightly pull in your navel. With one hand, feel the arch in your lower back. Squash that arch into the floor using your hand for feedback. This is called a pelvic tilt.
- Hold the pelvic tilt position, and then lift your bottom off the floor as far as is comfortable, without straining your neck and shoulders.
- Repeat the movement 10 times.
- If you find raising your bottom too difficult or you can't hold the pelvic tilt, just practise the pelvic tilt movement with your bottom on the floor.



Balance exercise

10. Standing balance:

- Stand near a work surface or wall.
- Stand **with your feet together** keeping an upright posture. Hold for as long as possible using fingertip support on the work surface/wall as required.
- If you are able to, keep this position and turn your head right and left. Repeat the movement 10 times.
- If this is easy, extend your arms and rotate them around to the right and left. Repeat the movement 10 times.



General benefits of exercise

Physical activity not only contributes to well-being, but is also essential for good health. It is not just your physical health that can benefit from physical activity; your mental health can benefit as well.

All in all, physical activity is one of the best tonics available. And yet in the past 25 years we have done less and less of it – with walking and cycling falling by a quarter. And despite what we say, this decline in physical activity has less to do with the ‘modern world’, but more to do with our attitudes. We are less inclined to do activities that take effort and prefer to drive a car, or stand on the escalators.

Before exercising

Before you start to do any exercises, think about the following:

- Have you talked to your physiotherapist, family doctor or gym instructor about the right exercises and level for you?
- If needed, have you considered orthoses? The right one can make exercising more efficient and enjoyable.
- Remember to pace yourself – don’t overdo it. And if you have worked hard one day, think about relaxing the next.
- Put together an exercise plan – build up slowly so as not to injure yourself. (The 10% rule is a good one to stick to – aim to increase your exercise levels by no more than 10% to 15% each week.)

Benefits of regular physical activity

- Overall reduces the risk of premature death by up to a third.
- Reduces the risk of coronary heart disease, stroke and type 2 diabetes by up to half.
- Combined with a balanced diet, it is the best way of keeping to healthy weight.
- Reduces the risk of osteoporosis.
- Helps treat mild to moderate depression.
- Helps people feel better and helps to beat stress and give you a good night sleep.
- Helps to keep our mental faculties sharp, particularly into old age.
- For older people, regular physical activity reduces your risk of falling and of being seriously injured.)

Questions and answers

I've heard that over exercising (overwork) can actually be harmful. Is this true?

Research into conditions such as CMT has shown that there is no increase in weakness with low to moderate intensity exercise, with the benefits far outweighing the risks. You can reduce your risks by:

- exercising at low to moderate levels, as advised by your gym instructor or physiotherapist
- not exercising to exhaustion
- recognising that if your muscles are sore for longer than 48 hours after the exercise that you have probably worked too hard.

Will any muscle that I build up rapidly waste away due to CMT?

Muscle wasting associated with CMT is slow and will tend to be at the extremities (hands and lower legs). If, for example, you built up your upper arm strength through weight training, we would not expect you to lose this effect due to the CMT if you have the more common types of CMT. However do remember that any muscle will lose strength if you stop exercising it. If you don't use it, you lose it.

Are there any parts of my body that I shouldn't exercise?

There are no parts of the body to avoid, although it may appear from research studies that there is little benefit to trying to strengthen severely weak muscles. However, physiotherapists would recommend general exercise as well as (or instead of) weight training, particularly exercise that strengthens muscles is important for good posture and balance, such as yoga, Pilates and Tai Chi.

Am I able to do weight training?

In the past there has been some argument whether people with CMT should do any weight training, but studies show that low to moderate intensity weight training improves upper and lower body strength with few injuries. The key is not to overdo it, probably using lighter weights with between eight and 15 repetitions.

Before starting any weight training – ideally before you start any exercise – you should talk to a gym instructor or physiotherapist to help you start at the right level. Advice from a professional will ensure that you perform the exercise in an optimal and safe position for your muscles to work effectively. This is particularly important if you have any reduced sensation in your arms or legs.

How much is a good thing?

The health and well-being benefits that we gain from exercise only last for a short time. If you stop exercising you will quickly begin to lose the health benefits. This is one good reason that we need to exercise regularly – doing a little often – rather than doing a lot of exercise now and then.

In order to benefit from exercise the general recommendation is that we all need at least 30 minutes of moderate intensity physical activity five times or more a week. But that doesn't mean it can't do you any good if you can't achieve that much. If you are at a lower level, and try to increase your level of activity over time, it should still be beneficial. Even chair based exercises can help.

You may find it helpful to rate how hard you are working on a scale such as the one below (the Borg scale):

6	
7	Very, very light
8	
9	Very light
10	
11	Fairly light
12	
13	Somewhat hard
14	
15	Hard
16	
17	Very hard
18	
19	Very, very hard
20	

The words describe how hard you feel you are working when exercising. Light exercise would be working at levels 11-12. Moderate exercise would be levels 13-14.

In general the amount of exercise that we need varies with our age. Adults need between 45 to 60 minutes of moderate exercise every day to prevent obesity (you do not need to do this all at once, but over the course of the whole day). Children and young people should be getting 60 minutes of moderate exercise over the day, every day, as well as doing two activities a week of

higher impact exercise – such as running or sports - in order to develop bone health and muscle strength and flexibility.

Older people should exercise as often as younger adults but with a focus on strengthening and balance exercises. As we get older we slowly lose muscle and our ability to balance is less effective. (Studies have shown that regular physical activity reduces your risk of falling and of being seriously injured.)

It's all very well going on about walking, but I find it tough. What would you advise?

If you find walking difficult, then you may find that swimming, or water-based exercise, is the answer. Even if you can't swim! This is because water-based exercises take the pressure off your joints. Talk to your local leisure centre about activities appropriate for you.

Further Reading

Charcot-Marie-Tooth: A Practical Guide

An essential guide to understand CMT, how to manage and treat the condition, and gives a wealth of practical information, including a directory of sources of further information.

Available in a loose leaflet binder or on CD-ROM

This is a publication produced by CMT United Kingdom.

Available by mail order – either phone below or from www.cmt.org.uk/shop



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