

How to Exercise with CFS

‘To equip people affected by CFS / ME with the skills for self-management towards a better quality of life’.



Pride in our older people's and adult community services

HOW CAN I EXERCISE WITH CFS/ME?



Many people with CFS/ME have been put off exercising and activity by previous ill-advised advice to go to the gym or start swimming, which has taken no account of their illness and current lack of fitness. This may have been from someone with little knowledge of CFS/ME. Others have decided for themselves to resume exercise but have started at a level that relates more to their level of fitness before CFS/ME rather than their present condition. This leaflet aims to help you understand some of the effects of inactivity on your body and how you can realistically go about gradual reintroduction of or increase in exercise without making your CFS/ME worse.

The effects of CFS/ME on the body

The onset of symptoms of CFS/ME forces a person to rest more initially and resting gives some relief. When that resting continues over a prolonged period with irregular bouts of activity, physical changes occur in the body which can lead to increased symptoms.



Look at the following effects of prolonged rest on the body and think about whether any apply to you:-

Muscle weakness. Bed rest can lead to muscles weakening at the rate of about 10% per week. A weakened muscle rapidly becomes uncomfortable when it is used and this discomfort can last for several days.

Joint stiffness: making movements restricted and uncomfortable.

Cardio-vascular changes (heart and blood vessels) which can cause nausea and dizziness, palpitations, fatigue and shortness of breath.

Increased sensitivity of nerves that is felt as pain.

Sluggish digestion.



Disturbance of body clock which can lead to difficulty sleeping at night and increased sleepiness during the day.

Changes in weight

Dulling of mental functioning causing difficulty with memory and concentration.

Lowering of mood as a result of reduced endorphin production.
The good news is that these effects are reversible!

Getting fitter

What is the right level of exercise that will not make my symptoms worse? The body adapts gradually to what is being asked of it. If you do less you will become less fit. If you continue to do about the same your fitness will remain constant. To get fitter you need to be regularly doing just a bit more than you normally do. If you do a lot more you will experience a level of discomfort that will discourage you from trying again. The most difficult aspect of getting fitter after CFS/ME may be coming to terms with a very low starting amount of exercise and being patient about increasing this very slowly. Getting fitter does not mean you have to start jogging or go to the gym. It involves doing a small amount more than you are doing at present, doing it regularly and building up very gradually. **A small amount extra, done regularly, will be the most effective way of getting fitter.**

What is your present level of activity/exercise?



Consider how physically active you are in an average day. This might include walking, housework, DIY, gardening and physical demands of work and/or childcare. If it varies a lot from day to day, think about how much it adds up to over a week and then divide by 7 to get your daily amount. It is important to be realistic about how active, or not, you are so that you start exercising in a way that is right for you as you are now.

Record roughly how physically active you are per day here. Is it only 10 mins or is it 4 hours or more? Remember we are talking about all physical activity not just things people usually describe as exercise.

.....
.....
.....

Which of the following best describes you?

A) I spend most of my time resting at home. Yes/No

B) At times I push myself hard then rest for long periods to recover. Yes/No

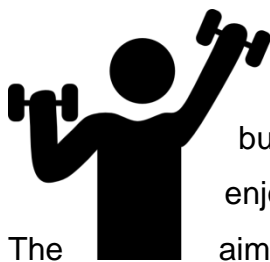
If it is A improving your fitness will involve making a very small increase to what you are doing, for example adding in 2-3 stretch exercises per day each done once without repetitions. This would only take 15-30 seconds per day. You can then build this up gradually adding in one extra stretch after a couple of weeks and increasing slowly. Even this may cause some initial discomfort, but this is not dangerous and will subside as your body adjusts to what you are asking it to do. Over a period of months you can extend the stretching regime and then start to add other exercise such as a walk down the garden and back.

For some people this will be too slow, it depends on what your starting point is. So if you can already walk for 10 mins most days without much difficulty, for example, you would start from that point and gradually increase it to 11 mins and later 12 mins. If you have a CFS/ME specialist or therapist it would be good to discuss this with them.

If the answer is B it is not feasible to start adding more activity to your schedule until you have your present activity under control. This means having a fairly regular pattern of activity and not alternating excessively active days with days of exhausted rest (boom and bust pattern). There needs to be a degree of confidence that you have a bit of spare energy to invest in getting fitter. If you answered B what do you need to do to get things onto a more even keel so that you can start to move forward? (Breaking up activities, resting at regular intervals for example).

.....
.....
.....
.....

What sort of exercise should I do?



Learning to do some stretches initially is a really good idea to wake up your muscles and unlock any tension that has started to build in your body. Later you can add any form of exercise that you enjoy for example low intensity walking, gentle cycling or swimming.

The aim is to gradually and gently build up your stamina over a period of time.

I am worried that exercise may make me worse

You may be worried that any increase in exercise or physical activity could make your condition worse. Be reassured – research has shown that a guided, gradual increase in exercise can help people who suffer from CFS/ME without causing ill effects.

I tried to increase my exercise before and it didn't work

In the past you may have been unable to improve your symptoms using an exercise programme, or you might have felt that exercise aggravated some of your symptoms. There may be a number of reasons why exercise did not work for you before. You may have started at too high a level of physical exercise, or increased the amount you did too quickly. You may have used an exercise that was too challenging for you now such as jogging, which you could do perfectly well before you became unwell. Or maybe you added exercise in

before you had stabilised your daily routine and learned to pace yourself, and while you were not getting enough good quality sleep or were stressed, these things could also have led to a bad experience of exercise.

How does this work in practice?

It is very important that you carefully work out how much of your new exercise/physical activity to do during your first week of adding exercise. Most importantly start at a level that you think you can do four or five days a week, **even on your bad days**, while still managing your daily tasks. This will be your exercise baseline. For example, Zoe can walk for 20 minutes three days per week but on a bad day she can only manage 10 minutes. **Zoe's exercise baseline would be 10 minutes, five days per week.** This is achievable even when she is not feeling at her best.

Some days your exercise may seem easy and it is tempting to do more. **Don't.** At this stage you should stick to your exercise baseline to avoid a boom-bust pattern. Do what you have planned to do, not what you feel you can do. It is important that your activity is undertaken at an easy and gentle pace. Increases in exercise duration and intensity will come later.

You should take a short rest after exercise. This gives time for your muscles and cardiovascular system to recover before your next activity and allows you to relax. However, you should avoid resting for longer than 30 minutes and try to avoid falling asleep.

Important point about your exercise baseline!

If your exercise baseline cannot be done at least five days per week then it is too high, re-adjust it to a level you feel you manage.

How often should I increase my exercise?

This can be dependent on a number of factors, but if you are generally pacing well and have limited stress going on in your life then increase your exercise baseline by about **10% every 3 weeks.** (That would be from 5 mins to 5 1/2 mins for example)

When should I not increase my exercise?

If you are experiencing a setback or have a virus or are maybe experiencing higher than normal levels of stress, it may be wise to stick to a lower exercise baseline until you start to feel better again. There are no medals for "pushing through" when we

don't feel well. Learn to be kind to your body and it will return the favour!

What if I get an increase in symptoms?

You may be worried about what is a normal compared to an abnormal response to exercise. Increases in breathing rate, heart rate and sweating are all normal, temporary responses to physical activity and exercise. Your muscles can feel heavy after exercise, and you may feel physically tired. With CFS/ME these feelings of physical tiredness can be more intense, but they will also help you sleep. A mild stiffness in the muscles is also normal after exercise and does not indicate harm to your body. If a reaction is extreme or prolonged then the level of exercise was probably too high. Don't give up altogether but take a day or two off, then try again at a lower level.

In summary

Graded exercise is an important part of the recovery process but it is important that you follow the guidance to ensure success. Start slow and build gradually. Always think can I do the level of exercise I am expecting of myself to do today MOST days? If the answer is NO you have set your level too high so aim to lower it even if it feels less than what you think you can do. The aim is to be able to do the exercise at least 5 days a week without causing a setback so it is important to start slow and after several weeks managing at the level you have set increase by about 10%.

Now start to think about you exercise goals and how you would like to achieve them.

.....
.....
.....
.....
.....
.....
.....
.....
.....

Ollie's story:

I was 20 when I started to feel more fatigued, I would come home from Uni tired and lay on the sofa before pushing myself to get up and get going again. It seemed to creep up on me gradually but I remember after I got flu when I was 21 I just seemed to really start to struggle to get back to my normal activities. I had just joined a local football team and was really enjoying playing matches at weekends, I used to go to the playing field most nights to meet up with my mates to play a game, but I started to notice that after half an hour I was not feeling very well and would go home. I got so frustrated at not being able to do what I wanted to do I stopped playing all my sports.

It was a few months before I saw a specialist and got the advice you are now reading about. It all helped me to start improving my fatigue. The thing I really wanted to do was play football again but I was advised to build this up gently and gradually. I'd been doing it all wrong because I would do way too much when I felt a bit better then suffer for it later! It was hard to learn to pace myself initially and trust me I got it wrong as many times as I got it right, but I stuck with it and noticed my energy levels improve. The key was to not charge off and do too much too quickly so I just started by going for regular short walks with the dog and over the weeks I got stronger until I was eventually able to go back up to the park and play a fun match for 10 minutes (usually in defence or goal as I wasn't up to running the whole time!) I'm really enjoying being able to do that again. So my advice would be to stick at it, even if it sometimes doesn't feel like you are making much progress, the small steps to getting fitter are the most important.

Adult CFS / ME Service

Tel: 0330 7260077

Press 2 for Huntingdon area
Press 3 for East Cambs and Fenland area
Press 4 for Peterborough area
Press 5 for Cambridge area

Email: cpm-tr.cfsme@nhs.net

Leaflet published: May 2019
Leaflet review date: May 2020

Patient Advice and Liaison Service

For information about CPFT services or to raise an issue, contact the Patient Advice and Liaison Service (PALS) on Freephone 0800 376 0775, or e-mail pals@cpft.nhs.uk

Out-of-hours service for CPFT mental health service users

Please call **NHS 111** for health advice and support.

If you require this information in another format such as braille, large print or another language, please let us know.

CPFT supports the **HeadtoToe Charity** – visit www.HeadToToeCharity.org for details on how you can help



HQ Elizabeth House, Fulbourn Hospital, Cambridge CB21 5EF
T 01223 219400 F 01480 398501 www.cpft.nhs.uk



A member of Cambridge University Health Partners