Physiotherapy Q&A

PhysiosforME are a group of physiotherapists in the United Kingdom with a special interest in Myalgic Encephalomyelitis ("ME")

Physiotherapy has had a very negative press and has often been seen to do more harm than good to a person with ME. What physiotherapy is suitable for a person who is bedbound with very severe ME?

This is a tricky one to answer because everyone is different. We can't treat 'ME', but we can treat the problems caused by the disease. One example is monitoring range of movement at the muscles and joints, because being bed bound can make them very stiff. This can be particularly problematic in the calf muscle as when you lie down the ankles and feet have a tendency to point, which shortens the calf muscle. If a muscle becomes too short and 'stuck' we call this a "contracture" and the only way to fix a contracted muscle is through splinting or even surgery. So for anyone that is bedbound, it's important to keep the muscles and joints flexible to prevent these complications. We can do this by moving the limbs and joints passively, but we know that not all people with ME can tolerate this. So, we may also look at positioning aids to support the joints in a better position.

Other physiotherapy could include breathing exercises, core stability exercises and circulation exercises, to prevent complications such as a DVT. But any 'exercise' prescribed for someone with severe ME needs to be carefully thought through, with constant monitoring to avoid worsening of symptoms.

If someone with ME is bedbound but may be coming out of a relapse, or is feeling more well, then physiotherapy can support the person to become more mobile. This might be through strengthening exercises, but mostly through helping the person to re-learn how to move in bed, how to sit up in bed and to become more independent within the bed. This can be a long process and it has to be at the right time for that person. If someone is in a relapse or is unable to tolerate anyone in the room, then options for physiotherapy are very limited, but we can advise on the best and safe way to support that person with moving and handling.

How do I find a physiotherapist with understanding of ME? Are they available on the NHS and will they come to the house?

There are specialist NHS Fatigue services across the UK that may offer home visits (although this may not be available in current Covid times). You can get a referral via your GP and ask whether they offer home visits. Another option is asking for a community physiotherapist to visit. A non-specialist team will not necessarily understand ME, but if they are open to learning and working with you, it could still work. You can always direct a physio to our website so that they can update their knowledge.

ME is classified as a neurological condition by the World Health Organisation, and there are physiotherapy services that specialise in neurology. Unfortunately we know that training on ME is very limited in most physiotherapy courses, so even if a physiotherapist is specialised in neurology it does not always mean they have experience with ME, but neurological physiotherapists work with people who have long-term conditions with complex needs, so their skillset is more suited particularly to severe ME.

There is also the option of a private physiotherapist, and you can find both musculoskeletal and neurological therapists who work privately and offer home visits. There is no guarantee that a therapist will have knowledge of ME, but a good physio is willing to listen, learn and understand. Before enlisting a private physiotherapist, it is a good idea to talk to them first to find out what experience they have. We are planning to put up a list of questions on our website that can be used to start this conversation with a potential physiotherapist and will post the link soon.

Are there resting positions which will alleviate pain for a person who is completely bedridden? Will all physios know about these?

This is tricky to answer again as it really depends on where the pain is. All physios should know how to help with posture and positioning for pain but most would agree that a regular change of position is the most important thing for all types of pain, whether the pain is isolated to one joint or all over the body. There are positions in side-lying, supine lying (lying on your back) and in a slightly elevated/sitting position (if able) that can be alternated, but we know this isn't always possible for people with ME who are very severely affected. Most physios would advocate an electric profiling bed and a good pressure relieving mattress to help with pain and care.

I have heard the terms 'passive' and 'active assisted' exercises. What does this mean?

Passive movements are when someone else moves a limb for you, so you don't use any energy to move yourself. The person who carries out the passive movement needs to be trained to do this, otherwise they may over-stretch or cause more pain if they don't understand how far each joint is supposed to move. Physios are generally happy to train a carer to do this, but it is not as easy as it sounds and could take a few sessions until the physio and the carer feel comfortable and confident.

Active-assisted movements are when you move yourself but are facilitated by another person, often with them taking most of the weight. This type of movement can allow you to use your muscles to move, but without having to support them completely against gravity.

An active movement is when you do all the work yourself, without any help from someone else.

I spend most of my time lying down, mostly on my front. I have lower back stiffness/pain. Any advice or gentle exercises I could do?

Because everyone is individual, it would be important to assess you properly to figure out why you have low back pain/stiffness. What is important to think about if you are lying on your front is how soft or hard the mattress is. For example, if it is soft and you sink into the mattress, your back is likely to be very arched which may be causing the pain. General advice would be to move and change position regularly to see if this helps.

Can you recommend any very gentle exercises I can do in bed?

It is not possible (and not within our professional standards) to prescribe exercises without assessment, especially for a condition like severe ME. Exercise should be individually prescribed depending on need and tolerance. Changing positions regularly is a good start, however.

I am bedbound and completely non weight bearing. I can no longer pull my feet towards me and they are starting to point down. What is this and is it something I can address myself? (Please could you mention not having the weight of bedclothes on feet)

See our answer above about contracted muscles. It might help to put a pillow at the bottom of your feet to prop them up and prevent the toes and ankles from pointing down. If this doesn't work, please ask your GP for a physiotherapy referral as you may need splinting and stretches to prevent it from getting worse. It might help not to have the weight of a duvet/bed clothes on your feet, as this will pull them further downwards.

I am very hypermobile. Is it possible for physiotherapy to make me less hypermobile?

Physiotherapy cannot fix hypermobility as it's the collagen in the muscles, ligaments and connective tissues that is more lax than usual. However, physiotherapy can help to manage hypermobility by using strengthening exercises, core stability/pilates type exercises and cardiovascular exercise to help. This is obviously so very difficult for people with severe ME, but low level strengthening in the form of isometric (static) muscle contractions might help. Any exercise needs to be prescribed based on the individual, so a thorough assessment would be needed first.

Lying on my back for many years has "ironed" the natural curves out of my spine so when I stand up, my back is dead straight. Is it harmful in any way not to have these curves and is there any way I can get them back? If I lie on my side, my shoulders hurt.

We have natural curves in our spines to allow us to hold an efficient posture when we are upright against gravity. These curves are held and maintained by the action of our postural muscles that run along our spine. Every person has a slightly different shape to their spine, which is dependent on lots of factors such as size, shape, and whether muscles are strong/weak, or long/short.

Not being upright against gravity for a long time could make postural muscles weak, because they are not having to work. This could then change the shape of the spine. As long as this does not cause pain or discomfort, then it is not too much of an issue. If an anti-gravity position becomes tolerable, then the postural muscles can be retrained again – either through gradual increases in time spent upright, or through targeted exercises.

Graded Exercise Therapy has been taken out of the Draft of the NICE Guidelines. Is the 'Energy Management Plan' just a replacement for this and who would you want to see overseeing such 'plans'.
This is a great question! We wrote a very detailed response to the NICE draft, which is available to read in full here: **https://tinyurl.com/495b2a8d**

While we were overall pleased with the draft, we did raise our concerns at the inclusion of a separate section of "physical activity" and suggested it should be incorporated into the energy management plan, with the recommended wording:
"Only consider physical activity for people with ME/CFS as part of a maintenance plan for activity and energy management to support activities of daily living. The means to measure post exertional symptom exacerbation must be put in place prior to any new activity being introduced, and if progression is considered then monitoring is essential to avoid exceeding the anaerobic threshold and associated post exertional symptom exacerbation."
We also raised the issue about training and that there should be more specific wording. Our suggested wording was:
"Any physical activity within an activity management plan should be overseen by a physiotherapist or occupational therapist who has undertaken current, evidence-based training in exercise physiology relating to ME/CFS and can evidence their continuing professional development within this speciality. An awareness of the abnormally lowered anaerobic threshold, lowered VO2 max, increased acidosis post-exercise and their implications are essential.
Training should reflect the low to very low quality of evidence relating to GET and the additional recent evidence related to adverse physiological responses to exertion and the implications for this on activity management planning."
We await with anticipation the final version, whenever that may be!

We would like to thank Physios for ME for taking the time to provide such detailed responses to the questions asked.