



Medication for individual symptoms

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Introduction

While there is no single pharmacological cure for ME, despite the efforts of dedicated scientists and clinicians around the world, there are a number of medications that your doctor can prescribe that may help with individual symptoms.

In some cases, this may include those licensed primarily for other health conditions.

Different drugs have different effects on symptoms, and they also differ in their side effects.

If you find that a drug is ineffective or cannot be tolerated, it may be worth systematically trying others, as directed by your GP.

People with ME often have a limited tolerance to drugs, so starting lower doses than usual may be needed, then slowly increasing if appropriate, and only with support from your health professional, who should also be aware of potential issues around polypharmacy (see below).

If you take prescription medication regularly, you can ask for a review at your local pharmacy.

NICE guideline advice

The [2021 NICE guideline for ME/CFS](#) advises the following regarding medication:

"1.12.16 Offer people with ME/CFS a medication review in line with the NICE guidelines on medicines adherence and medicines optimisation.

"1.12.17 Take into account when prescribing that people with ME/CFS may be more intolerant of drug treatment. Consider:

- starting medicines at a lower dose than in usual clinical practice
- gradually increasing the dose if the medicine is tolerated.

"1.12.18 Drug treatment for the symptoms associated with ME/CFS for children and young people should only be started under guidance or supervision from a medical professional trained and experienced in paediatric prescribing."

A word about anti-depressants

Some tricyclic antidepressants are prescribed in low doses to help with sleep (see below).

It has also become increasingly recognised that they can help in the management of chronic pain.

Using antidepressants does NOT mean that ME is the same as depression, or that it is a mental illness.

The doses used to help with sleep and pain are much lower than the doses used to help manage depression.

If you are experiencing depression as a consequence of coping with ME, or other conditions, then please consult a health professional about this.

Medication for pain

Our 2019 Big Survey of more than 4,000 people with ME found that 68% of people use medication for individual symptoms.

It can be challenging to tell the difference between different types of pain, such as muscle pain, pain from the joints, or pain related to nerves.

Often people can feel pain in their legs which is actually related to arthritis or the trapping of nerves in their back.

So, sometimes it can take a bit of investigation by your GP in order to determine the site of origin of the pain, and how to treat it.

With regards to pain in the muscles, this is sometimes there at rest but can frequently occur after activity (i.e. post-exertional malaise).

A compulsion to move, or a crawling sensation in the skin, when you wake from sleep may be indicative of something like restless leg syndrome, which is a condition that seems to be more common in people with fatigue-associated conditions.

A variety of painkilling drugs act in different ways to control different types of pain. These include paracetamol, non-steroidal anti-inflammatory drugs (NSAIDs, such as ibuprofen), opiate based painkillers, tricyclic antidepressants and others.

Please note that not all these interventions are of proven benefit, and some may have side effects.

We always advise that you consult a medically qualified practitioner before trying any new medications or changing any dose of existing medication.

Medication for sleep

Medication should be used to kick-start the process of improving sleep.

Using medication long term can lead to dependency, though each individual is different, and you should always seek advice from a health professional if you have any concerns.

There are three main types of prescription medication for helping with sleep:

1. Hypnotics. These are the traditional sleeping tablets. The shorter-acting ones, such as Zopiclone, tend to be less addictive, but should still only be used in short courses (around two weeks) and beyond that, only used intermittently. They are helpful if you have difficulty getting off to sleep. All sedatives can impair concentration, and some can lead to excessive sedation the following day.
2. Tricyclic antidepressants and Trazodone. Amitriptyline is the most often prescribed of these medications. That and Trazodone were developed many years ago as antidepressants; it was noted, however, that they also helped promote a better sleep pattern. Furthermore, it has become increasingly recognised that they can help in the management of chronic pain. As pain can be a major factor for people with ME in reducing quality of sleep, these medications may prove useful. The doses used to help with sleep and pain are much lower than the doses used to help manage depression.
3. Melatonin. This is a naturally occurring hormone produced in the body. It is produced in the pineal gland, and its function is to regulate sleep. It is now available as a medication and can be prescribed on the NHS (it is currently licensed for people over 55). Again, it is recommended that it be used short-term to help promote a better sleep pattern. Some people with ME have reported benefits from taking it. It has been noted, though, that it can adversely affect diseases of the immune system.

It's important to start with the lowest possible dose and monitor effects on sleep and daytime tiredness before making any increase in the dose.

Medication for orthostatic intolerance

The 2021 NICE guideline for ME/CFS says:

- “1.12.9 Be aware that people with ME/CFS may experience orthostatic intolerance, including postural orthostatic tachycardia syndrome (POTS).
- “1.12.10 Medicine for orthostatic intolerance in people with ME/CFS should only be prescribed or overseen by a healthcare professional with expertise in orthostatic intolerance.
- “1.12.11 Refer people with orthostatic intolerance to secondary care if their symptoms are severe or worsening, or there are concerns that another condition may be the cause.”

Issues with polypharmacy

A significant number of people with ME take medication for individual symptoms.

However, organising and taking medication, along with coping with side effects, may add to the burden of ME.

Although sometimes appropriate, polypharmacy could occur due to the following factors in someone with ME.

The symptom management approach can result in many medicines being prescribed over time due to the numerous symptoms of the illness.

People with ME can attend many different specialists, especially during investigations at the start of the illness to establish a diagnosis, and each may prescribe medication.

Increased susceptibility to side effects, and the similarity of these and the symptoms of ME, can result in misinterpreting these as new symptoms and medication being prescribed to alleviate them, resulting in a prescribing cascade.

A high occurrence of multimorbidity can contribute to the number of medicines prescribed.

Some symptoms may come and go over time, so it is possible that the indication for which medication has been prescribed is no longer current.



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