



MANAGEMENT FILE

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This leaflet is based on an article which first appeared in the ME Association's quarterly *ME Essential* magazine. MEA membership costs £18 a year for people living in the UK/BFPO. For contact details, see foot of this page.



LYRICA/PREGABALIN FOR PAIN RELIEF IN ME

Lyrica is the trade name (pregabalin is the generic name) for a drug that can be used to treat three different conditions – epilepsy, nerve pain and anxiety.

In relation to pain, Lyrica is used for moderate or severe pain, especially nerve (neuropathic) pain, that is persistent and which has not responded to other types of painkillers.

Lyrica can be used alone or in combination with some other types of painkiller.

WHAT ABOUT ITS USE IN ME/CFS?

Patient feedback (146 responses) on the use of Lyrica in the pain section of the MEA Management Report found that the effect was:

- Good in 16%
- Moderate in 22%
- Poor in 10%
- No change in 23%
- Worse in 29%

In The MEA September 2014 website poll on pain relief, Lyrica was reported by 7% of people (22/310 votes) to be the most effective form of pain relief that had been tried.

And, in a discussion in September 2014 on MEA Facebook, some people found Lyrica helpful, and in a few cases found it very helpful. However, the majority reported that it had been of little or no benefit, or that problems related to side-effects had outweighed

any benefits. One of the most commonly noted side-effects was weight gain. In one case, a severe skin reaction had occurred.

There have not been any clinical trials to assess the value of Lyrica in ME/CFS.

HOW DOES LYRICA WORK?

Although not fully understood, Lyrica appears to work through binding to what are called calcium channels on nerve cells in the brain and spinal cord. This causes a reduction in the release of three neurotransmitters (chemicals that transmit messages around the nervous system) called glutamate, noradrenaline and substance P.

Glutamate is a 'nerve-exciting' chemical transmitter and helps to cause epileptic seizures. Reducing the level of glutamate from nerve cells stabilises electrical activity in the brain and helps

to prevent epileptic fits occurring.

Glutamate, noradrenaline and substance P are all involved in transmitting information about pain around the brain and nervous system.

So reducing the level of these three chemicals can also help to reduce pain – especially neuropathic or nerve pain, which has a burning, shooting, stabbing or searing quality. There is also some evidence to show that Lyrica can help with other types of pain as well.

These three neurotransmitters are also involved in anxiety disorders – so Lyrica can also be used to treat anxiety.

HOW IS LYRICA TAKEN?

The drug can be taken in capsule or liquid form – with or without food.

It is usually taken two or three times a day – preferably at regular intervals – and at the same times each

NEW PRESCRIBING GUIDANCE FOR LYRICA

Due to growing concerns about misuse, the legal status of pregabalin (trade name = Lyrica) has changed and these changes came into effect in April 2019. This drug is now classified as a Class C Controlled Drug.

This means that there are additional restrictions on the way in which doctors are able to prescribe gabapentin.

Restrictions include prescriptions being limited to 30 days treatment and repeat prescriptions no longer being allowed.

And as a result, some doctors are likely to take a far more cautious view about prescribing gabapentin for pain relief in ME/CFS.

More information on these changes can be found in this MEA website statement: <https://tinyurl.com/y3gondvb>

day, which helps to prevent 'missed doses'. If you forget to take a dose do so as soon as possible. But if it's nearly time for the next dose don't take a double dose. The dose will depend on individual circumstances.

Do not suddenly stop taking Lyrica. As with many drugs that affect brain chemical transmitter systems, a sudden cessation of treatment can result in what is called withdrawal symptoms. These can include insomnia, headaches, nausea, diarrhoea, flu-like feelings, depression, sweating and dizziness. The dose should always gradually be reduced over a period of at least a week – possibly longer in some circumstances.

Keep the drug in a cool, dry place away from direct heat or light.

WHAT ARE THE MAIN PROBLEMS TO BE AWARE OF?

- Common side-effects such as dizziness, sleepiness and blurred vision may affect your ability to drive or operate any form of machinery.
- Lyrica can increase the effects of alcohol
- There is a small risk of suicidal thoughts or intentions occurring – so do see your doctor if you notice any changes in mood
- Lyrica can cause skin reactions – peeling, itching – and allergic reactions. So do see your doctor if unusual skin symptoms occur, or if you notice any difficulty with breathing or swallowing, or notice swelling of the lips, face or tongue.



ARE THERE ANY CONTRA-INDICATIONS TO ITS USE?

Lyrica needs to be used with caution, or not at all, in the following circumstances:

- The elderly
- Heart or kidney failure
- Diabetes
- Pregnancy – where safety has not yet been established
- Breast feeding – because it is not yet known whether the drug can be passed to a baby via breast milk
- Children and adolescents under 18 – where safety and efficacy have not been confirmed

Lyrica contains lactose – so it should not be used by people with inherited conditions involving galactose intolerance.

WHAT ARE THE SIDE-EFFECTS?

As with any prescription drug, some people will experience side-effects. But these often lessen over the course of time as the body adjusts to the drug. In cases where side-effects outweigh any benefits, this will normally mean that the drug has to be discontinued.

Some of these side-effects overlap with symptoms of ME/CFS – so they may cause an exacerbation of some ME/CFS symptoms.

If a side-effect is becoming troublesome do talk to your GP or pharmacist.

VERY COMMON SIDE-EFFECTS – affecting more than one person in 10:

- Dizziness and sleepiness

COMMON SIDE-EFFECTS – affecting between 1 in 10 and 1 in 100 people:

- Fatigue
- Headache
- Insomnia
- Increased appetite and weight gain
- Constipation, vomiting, wind

- Euphoric mood
- Confusion, memory problems or disorientation
- Irritability
- Sexual problems
- Shaky movements and tremor
- Blurred or double vision
- Dry mouth
- Fluid retention

UNCOMMON SIDE-EFFECTS – affecting between 1 in 100 and 1 in 1000 people:

- Mood swings, abnormal dreams, hallucinations
- Panic attacks
- Sensory disturbances: burning, numbness
- Visual disturbances, eye pain, watery or dry eyes
- Increased heart rate
- Hot flushes, sweating
- Dizziness, fainting
- Shortness of breath
- Abdominal swelling, acid reflux
- Increased salivation
- Pain, stiffness, twitching or cramp in muscles
- Joint pain or swelling
- Low blood sugar
- Difficulty passing urine, incontinence

RARE SIDE-EFFECTS – affecting 1 in 1000 to 1 in 10,000 people

- Decreased white blood cells – neutropenia
- Loss of peripheral vision
- Cold hands and feet
- Cough, nose bleeds,
- Inflammation of pancreas
- Breast pain
- Painful periods or cessation of periods

CAN TAKING LYRICA AFFECT OTHER MEDICINES?

Always tell your doctor if you are

taking any other medicines or alternative treatments – herbal remedies for example – before starting treatment with Lyrica.

This drug does not normally interact with other medicines – but it could cause dizziness and drowsiness if combined with other drugs that have sedating side-effects.

Examples include sedatives such as lorazepam, muscle relaxants such as baclofen, and strong painkillers such as codeine or strong opioids.

FURTHER INFORMATION

The MEA Management Report can be downloaded free from our website:

<https://tinyurl.com/y25d8heu>

Paper copies can be obtained for a small cost by phoning our office 01280 818 968 during office hours on weekdays.

Medical information contained in this leaflet is not intended to be used as a substitute for medical advice or treatment from your own doctor.

The ME Association recommends that you always consult your own doctor or healthcare professional about any specific problem.

We also recommend that any of the medical information provided by The MEA in this leaflet is, where appropriate, shown to and discussed with your doctor.



ME CONNECT

The Support and
Information Service for
people affected
by ME/CFS/PVFS
and Long Covid



Freephone 0808 801 0484

For opening hours visit:
meassociation.org.uk/me-connect

Contact ME Connect
3 WAYS TO GET IN TOUCH:
by phone, email
or social media private message



HERE TO LISTEN

We are here to listen, validate and empathise with any issues you might be facing.



VITAL SUPPORT

We are here to help you reach an informed decision.



SAFE ENVIRONMENT

We provide a safe, confidential and understanding environment where you can be heard and understood.

We're here for you!



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