

Lithium for Cluster Headache

Lithium carbonate (Camcolit®, Liskonum®, and Priadel®) is a medication used to help prevent cluster headache. You need to take it every day. It is not licensed for use in cluster headache. Sometimes a medicine is used “off-label”. This means it is not officially licensed for this condition, but there is good evidence that it is safe and effective. Lithium is widely used by headache specialists and supported by clinical evidence.

Before Starting Lithium:

Your prescriber will consider several factors before prescribing lithium to make sure it's safe and suitable for you.

Before starting lithium, you will need blood tests to check your full blood count, calcium level, kidney function, and thyroid function. These tests are usually repeated every two weeks at the start of treatment. Once you are on a stable dose, they will be needed every 3 to 6 months.

In some cases, particularly if you have a history of heart problems, you may also be advised to have a heart tracing (electrocardiogram or ECG).

Please tell your prescriber if you have:

- Heart problems, especially those affecting heart rhythm (for example if you have been told you have prolonged QT interval)
- Have a personal or family history of a heart rhythm condition (such as Brugada syndrome)
- Kidney problems
- Thyroid problems
- Low sodium levels (for example due to dehydration or a low-salt diet)
- Addison's disease
- Have a history of passing large amounts of urine or excessive thirst
- Are at risk of taking too much medication (accidentally or intentionally)
- Are planning a pregnancy, pregnant or breastfeeding
- Are over 65
- Have epilepsy
- Have myasthenia gravis
- Have psoriasis
- Are taking diuretics (water tablets)
- Are receiving electroconvulsive therapy (ECT)
- Are unable or unwilling to have regular blood tests

Tell your doctor about **all other medications or supplements**, as lithium can interact with some treatments.

How Do I Take Lithium?

You will start on a low dose of lithium, which will be gradually increased. This helps your body adjust and reduces the chance of side-effects.

This leaflet reflects a consensus of current clinical practice as agreed by the British Association for the Study of Headache (BASH) Council. It is intended to provide information to support clinical decision-making and does not constitute prescriptive guidance that must be followed in all cases. Clinicians should continue to exercise their own professional judgement and tailor management to the individual. The content reflects the collective experience of headache specialists across the UK, whose contributions are gratefully acknowledged, and recognises the ongoing evolution of best practice. This leaflet should be read in conjunction with the Summary of Product Characteristics and the patient information leaflet provided with all medication.

The schedule below is a guide, but your prescriber may change it to suit your individual needs. Your prescriber will advise you on your starting dose.

Important: Only change your dose if your GP, specialist nurse or neurologist has advised you to follow this adjustment plan.

Starting dose: 100 mg twice daily

- On **day 7**, you should have a blood test to check your **lithium level, kidney (renal), thyroid function, full blood count (FBC) and calcium level**.
- Continue taking **100 mg twice a day** until **day 14**.
- Around **day 14**, check your blood test results.
- Your dose may need to be changed based on these results. Please review this using the dosing table and discuss any changes with your **prescriber or GP** before adjusting your dose.
- You will need to have a **blood test every two weeks** until your prescriber agrees you are on a stable and effective dose. This is typically when your headaches are controlled and there are no concerns about your lithium levels. More frequent blood tests, for example every week, may be needed if your lithium level is high (above 1.0 mmol/L).
- If you develop side-effects, please inform your prescriber as your medications will need to be reviewed.
- Check your results using the table above and adjust your dose if advised by your prescriber.
- Once you are on a stable dose and your lithium levels are within the target range, you will need blood tests every 3 months for the first year, and then at least every 3 to 6 months after that. Some people may need more frequent monitoring.

What should I do?		
●	Headaches controlled	Stay on your current dose unless advised otherwise
●	Lithium level between 0.8–1.0 mmol/L	Stay on same dose
●	Lithium level less than 0.8 mmol/L	If headaches are uncontrolled follow the dose increase guide below
●	Lithium level More than 1.0 mmol/L	Contact your healthcare team (the dose needs to be reduced)
●	Significant side effects	Contact your GP or specialist team do not increase lithium

How to take the blood test

Your lithium blood test should include a lithium level, kidney (renal) and thyroid function and should be taken:

- ✓ **At least 12 hours after your last lithium dose**
- ✓ For example take your evening dose before 9 pm
- ✓ Blood test performed following morning after 9 am
- ✓ **Before taking your morning lithium dose**

The maximum dose of Lithium is 1200mg per day.

Dose increase guide:	
Current dose	New dose if lithium level is below 0.8 mmol/L
100mg twice daily	200mg twice daily
200mg twice daily	300mg twice daily
300mg twice daily	400mg twice daily
400mg twice daily	500mg twice daily
500mg twice daily	600mg twice daily
600mg twice daily	Do not increase further without specialist advice

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Contact your healthcare team urgently if you develop

- Severe nausea, vomiting or diarrhoea
- Increasing tremor
- Marked drowsiness
- Difficulty walking or poor balance
- Slurred speech
- Blurred vision
- Confusion

These may be signs that your lithium level is too high.

How Long Should I Try It?

- You should continue to increase lithium following the guidance above until your headache attacks resolve or you are unable to tolerate the side-effects
- Your prescriber or GP will review your treatment regularly
- Do not stop taking it suddenly, as your pain may return or worsen and you may feel unwell
- If it is effective and you are cluster headache-free for at least two weeks, you should discuss with your prescriber reducing and discontinuing lithium by following the schedule above in reverse. If you have chronic cluster headache, longer-term treatment may be advised.

What Are the Possible Side-Effects?

Some people get side-effects. These usually get better as your body gets used to the medication. This is not a full list of side-effects. Please read the information leaflet that comes with your medication for more details.

The most common side-effects are:

- Nausea
- Vomiting and/or diarrhoea
- Loss of appetite
- Fine tremor
- Increased thirst
- Frequent urination
- Weight gain
- Swelling

If you feel tired or dizzy do not drive a car, ride a bike, or use tools or machinery

Pregnancy and Breastfeeding

If you are pregnant, planning a pregnancy, or breastfeeding, speak to your doctor, prescriber or pharmacist before taking lithium.

Lithium can easily pass into breast milk and The National Institute for Health and Care Excellence (NICE) and the British Association of Psychopharmacology recommend not to breastfeed whilst taking Lithium.

For more information, see: Best Use of Medicine in Pregnancy (BUMPS)

<https://www.medicinesinpregnancy.org/>

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