

Taking mepacrine for your systemic lupus erythematosus (SLE)

This information sheet has been given to you to help answer some of the questions you may have about taking mepacrine to treat your systemic lupus erythematosus (SLE). If you have any questions or concerns, please do not hesitate to speak to a doctor or nurse caring for you.

What is mepacrine?

Mepacrine was first introduced in the 1930s as a treatment for malaria. It is one of several antimalarial drugs that have also been found to have anti-inflammatory properties. These properties can help various conditions that cause skin inflammation, including SLE.

Mepacrine is unlicensed in the United Kingdom. This is because the numbers of patients taking mepacrine are very small and it is not cost effective for large pharmaceutical companies to manufacture. As a result mepacrine is made especially for the small numbers of patients who need it by a company called Boots Manufacturing.

Although mepacrine is unlicensed, the Lupus Unit at St Thomas' has used it safely for many years.

Taking an unlicensed medicine

The leaflet, **Unlicensed medicines – a guide for patients**, has more information about unlicensed medicines. If you would like a copy, please ask your doctor, nurse or pharmacist. Alternatively you can call the pharmacy medicines helpline – contact details are at the end of this leaflet.

Which conditions are treated with mepacrine?

SLE causes inflammation in different parts of the body. Mepacrine cannot be used for all types of lupus and is used particularly to treat lupus which causes skin inflammation, such as:

- **Discoid lupus erythematosus** – causes a rash with inflammation and scarring. Usually found on the face, ears, and scalp and sometimes on other areas.
- **Subacute cutaneous lupus erythematosus** – causes scaly patches on the skin. Usually found on sun-exposed areas such as the neckline or the forearms, but not the face.

For more information about SLE contact your Consultant, Specialist Nurse or visit the official St Thomas' Lupus Trust website www.lupus.org.uk.

How do I take the medicine?

Doses vary from person to person and your doctor will advise you about your dose. The dose may be as small as 50mg (half a 100mg tablet) taken three times a week. A maximum dose would 100mg taken three times a day.

You may find the tablets taste bitter. It may take several weeks to reach its full effect so you may not experience benefit immediately but it is important to keep on taking your mepacrine.

What should I do if I forget to take the medicine?

There is unlikely to be any harm from missing a single tablet of mepacrine. You should simply take the next dose when you remember. There is no need to take a double dose to make up the missing dose.

What are the possible side effects of mepacrine?

At the low doses used to treat SLE, most patients can take mepacrine without major problems. Like all medicines, people can experience side effects with mepacrine and these will vary from person to person. The side effects include:

- Yellow discoloration of the skin and urine may occur during long-term treatment or with large doses. This is common but quite harmless, and should not be a cause for concern, as it goes away when you stop taking the drug. Similarly, the roof of the mouth, nails and eyes may be discoloured blue or black.
- Mepacrine can cause dizziness, particularly when you get up from sitting or lying down. Getting up slowly should help.
- Other possible side effects include: tummy upsets, headaches, feeling and being sick, skin rashes (including severe rashes), and changes in mood or behaviour. Fits may occur with over-dosing. Liver inflammation and alterations in the blood count can occur but are rare.

How will I be monitored for the side effects of mepacrine treatment?

Blood tests may be performed about twice a year to check your blood count and how your liver is working. However, there is no need for very frequent blood tests as mepacrine does not suppress the immune system.

Some patients take mepacrine with another antimalarial drug called hydroxychloroquine. If you are taking hydroxychloroquine you will require annual eye checks but this is not necessary with mepacrine alone as it does not affect your vision.

Can I have vaccinations while I am taking mepacrine?

Yes, this should not be a problem. However mepacrine will not provide adequate protection against malaria, therefore you should see your GP (family doctor) about appropriate antimalarial treatment if you are planning to travel to a place where malaria occurs.

Does mepacrine affect fertility or pregnancy?

There is no data on the use of this drug in pregnancy and breastfeeding. However it is recommended that you should avoid taking it if you are pregnant or planning a pregnancy, or if

you are breast-feeding. If you think you are pregnant, or you are planning a pregnancy, please speak to your doctor.

May I drink alcohol while I am taking mepacrine?

Mepacrine has been reported to produce a mild flushing reaction when taken with alcohol. There may be symptoms such as a racing heartbeat, dizziness, headache, shortness of breath, and sickness.

Can I take other medicines at the same time as mepacrine?

Mepacrine is often used in combination with hydroxychloroquine (another anti-malarial used to treat lupus) for additional benefits. This is safe. However some drugs do interact with mepacrine. For example, mepacrine may increase the blood level of primaquine (an anti-malarial drug), resulting in a higher risk of toxicity, and it has been recommended that these two drugs should not be used together. Always inform your doctor and pharmacist if you are taking other medication.

Where can I get a repeat prescription?

Some patients will have their mepacrine prescribed and monitored by their GP in partnership with the hospital. This is called shared care. If your GP writes a prescription, you can take it to your local community pharmacy who can order your mepacrine from Boots Manufacturing:

BCM Specials

Tel: 01773 515599

www.bcm-manufacturing.com/bcm-specials1

Remember it may take some time for your tablets to be ordered in so arrange for repeat prescriptions a few weeks in advance to avoid running out. If your GP does not wish to share care with the hospital, you will need to continue to obtain supplies from the hospital pharmacy.

Contact us

If you have any unexpected side effects you should stop taking mepacrine and see your GP. You can also call the clinic lupus nurse specialist and leave a message on the Lupus Unit patient helpline on 020 7188 3549.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets.

Pharmacy medicines helpline

For information about any medicines that you have been prescribed at Guy's and St Thomas' hospitals, you can speak to the staff caring for you or call our helpline.

t: 020 7188 8748, 9am to 5pm, Monday to Friday.

Patient Advice and Liaison Service (PALS) – To make comments or raise concerns about the Trust's services, please contact PALS. Ask a member of staff to direct you to the PALS office or:

t: 020 7188 8801 at St Thomas' t: 020 7188 8803 at Guy's e: pals@gstt.nhs.uk

Language support services – If you need an interpreter or information about your care in a different language or format, please get in touch using the following contact details.

t: 020 7188 8815 fax: 020 7188 5953

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