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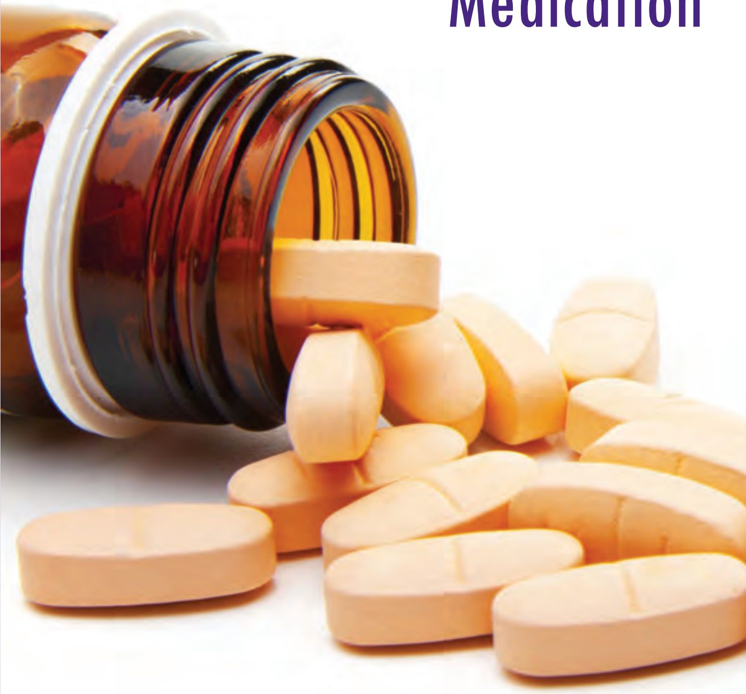
LUPUS
and
Medication



LUPUS UK

LUPUS
and Medication

This factsheet details some of the many drug treatment options for patients with lupus. It is primarily about the treatment of SLE. For more information on the treatment of cutaneous (discoid) lupus, see our booklet LUPUS and the Skin. It is important to remember that everyone's lupus presents individually and different drugs will be used to treat various symptoms. One patient may experience several different treatment regimens during her/his lifetime.

The types of drugs used in patients with lupus can be broadly divided into those that treat the disease itself by dampening down inflammation, known as disease-modifying drugs or immunosuppressants (e.g. hydroxychloroquine, mycophenolate, azathioprine and prednisolone) and those that are used to treat the other problems that are sometimes associated with lupus (e.g. tablets for high blood pressure, osteoporosis, high cholesterol and tablets to thin the blood in patients with antiphospholipid syndrome (sticky blood) as part of their lupus).

Non-steroidal anti-inflammatory drugs (NSAIDS)

These drugs may be used to treat pain when paracetamol alone is ineffective. There are many types and they are designed to reduce pain due to inflammation. Ibuprofen (Nurofen) and naproxen are two commonly used NSAIDs. In a patient with lupus, they may be used to treat arthritis (inflammation of the joints) and pleurisy (inflammation of the lining of the lungs).

They may occasionally cause serious side effects so it is best to take the lowest dose possible for the shortest period of time. NSAIDs may cause indigestion and in severe cases they may cause peptic ulcers (stomach ulcers and duodenal ulcers) and bleeding from the gut so the doctor may recommend that you also take a tablet to protect the lining of the stomach (e.g. omeprazole) if you are going to take a NSAID. NSAIDs may slightly increase the risk of a heart attack or stroke if taken regularly for long periods of time (e.g. years) so it is recommended that you do not take these tablets if you already have problems with your blood pressure and/or angina. They may also cause kidney problems so NSAIDs should be avoided in lupus patients who already have kidney involvement.

Antimalarials

The most commonly used drug in this group is hydroxychloroquine. It has a number of good properties which make it a very useful drug for treating lupus. It can improve joint pain due to inflammation, improve rashes and mouth ulcers and reduce fatigue. It also reduces the stickiness of blood and lowers blood cholesterol a little. It is safe to take during pregnancy and whilst breastfeeding.

Very occasionally hydroxychloroquine can cause damage to the back of the eye (retinal damage). However, recent studies have shown that when hydroxychloroquine is taken at the recommended doses based on a patient's body weight that this risk of retinal damage is very low. It is recommended that patients have an annual full eye check with an optician to ensure that they are not developing any eye problems related to hydroxychloroquine. The older drug chloroquine was associated with a higher risk of retinal damage so it is usually avoided now.

It is important to note that hydroxychloroquine takes a while to become effective; it may take 3-6 months for it to reach its full effect. It may be strong enough to treat mild lupus but the addition of other 'disease-modifying' drugs will be required in patients with moderate to severe lupus.

Corticosteroids (e.g. prednisolone)

Corticosteroids (steroids) can be life-saving and are very useful in the rapid, effective treatment of moderate and severe lupus flares (e.g. when there is new severe inflammation in the kidney, lung, heart, gut and/or nervous system). The modern treatment of lupus is geared to reducing the dose as soon as possible, and it is now known that the majority of lupus patients can be maintained either on a low dose or be weaned off steroids altogether.

Side-effects of using high dose steroids for a long time are well known and include weight gain, a "moon" face, development of diabetes, increased susceptibility to infection and thinning of the bones, known as osteoporosis. Risks with steroid use are highest with higher doses for longer periods of time so at an early stage other drugs will be added to help dampen down inflammation. As these immunosuppressants/disease-modifying drugs become effective, then the dose of prednisolone can be reduced. Sometimes during a flare, an injection of steroid may be given into the muscle (intramuscularly) or via a drip into a vein (intravenously). Rashes due to lupus may be treated with steroid creams.

Immunosuppressant/disease-modifying drugs (but not including the biological therapies which are covered separately - see below)

These drugs are used to reduce the need for steroids and to help to control moderate and severe lupus activity by dampening down the immune system. They may also be called disease-modifying anti-rheumatic drugs (DMARDs). The options include azathioprine, methotrexate, mycophenolate mofetil, ciclosporin, leflunomide and cyclophosphamide. They have different ways of working and so one drug may be more beneficial in treating a particular lupus symptom and/or level of disease activity than another. A drug should therefore be chosen to best treat an individual's lupus. Again it is important to note that these medications do not work immediately but can take six weeks to three months to become effective. They do not affect day to day symptoms but are used to control your lupus in the long term.

These drugs will usually require close monitoring with regular blood tests to ensure that the blood counts, kidney and/or liver function tests are OK. Some may also require blood pressure and urine checks. Usually you will start on a low dose of the drug and then increase the dose according to your response/severity of your symptoms. If you have an infection, and particularly if you require antibiotics, it is best to temporarily stop these drugs under the supervision of your doctor. If one of these drugs does not suit you, then another one will be tried. Live vaccines should be avoided but it is usually recommended that you have the annual flu vaccine and remain up to date with the pneumococcal vaccine. Alcohol can be drunk with these medications but it is recommended that you do not exceed the government's advice of drinking 14 units or less, spread throughout the week.

Some of these drugs can be continued during pregnancy and whilst breastfeeding (e.g. azathioprine) but others are harmful to the baby and should be stopped some time before trying to conceive (e.g. mycophenolate, methotrexate and cyclophosphamide). Please discuss this with your consultant and specialist nurse. It is best to plan when you wish to conceive. The pregnancy will be most successful if your lupus is well-controlled on a stable dose of a drug that is OK to continue during pregnancy.

Azathioprine has been used to treat moderate lupus for a long time. It is taken twice per day. It is safe in pregnancy and can be continued whilst breastfeeding. In a few patients, the bone marrow can be very sensitive to this tablet so a special blood test called the TPMT level may be checked before you start the tablet. TPMT (thiopurine methyltransferase) is an enzyme in the body that helps to breakdown azathioprine

Mycophenolte mofetil (MMF) is used to treat moderate and severe lupus including kidney disease. It is taken twice per day. MMF sometimes causes diarrhoea but this side effect can usually be reduced by decreasing the dose.

Methotrexate is another drug used to treat moderate disease, particularly arthritis and some rashes. It is not suitable for patients with kidney disease. It is taken weekly, usually as tablets but it is sometimes given by subcutaneous (under the skin) injection. Folic acid is usually given to reduce the risk of possible side effects such as a sore mouth and abnormal liver function tests. Occasionally methotrexate can cause breathlessness due to inflammation in the lungs. Your doctor is likely to ask you to have a chest x-ray and possibly lung-function tests prior to starting treatment. If you become breathless, you should stop methotrexate and contact your consultant, specialist nurse and/or monitoring clinic nurse so that you can be assessed urgently.

Cyclophosphamide is a strong drug and used to treat severe lupus e.g. kidney inflammation and inflammation of the brain. It is usually given by a drip into a vein in your arm or "pulse". It is a very effective drug and the newer regimes using lower doses and shorter courses have a much better safety profile than the older, higher dose regimes. Once cyclophosphamide has controlled the active lupus then another immunosuppressant (e.g. MMF or azathioprine) will be started in its place to maintain control of your lupus.

Possible side effects due to cyclophosphamide include nausea, a reduction in white cell count with an increased risk of infection and haemorrhagic cystitis (bleeding from the bladder wall). However there are ways of reducing these potential side effects e.g. taking anti-sickness medication, drinking lots of fluid on the day of the treatment and taking a tablet called mesna to protect the lining of the bladder. When higher doses are used and in an older patient, there is an increased risk of failure of the ovaries or sperm-producing cells, making the patient infertile (unable to have children) and/or causing an early menopause. These potential side effects will be discussed with you and the benefits and risks will be considered on an individual basis.

Ciclosporin may be useful to treat lupus patients with low white cells and low platelets. It can cause high blood pressure and affect kidney function so it needs to be monitored very carefully. It can be used in pregnancy and taken whilst breastfeeding.

The biological therapies

These drugs have been developed to target certain pathways in the immune system that are associated with inflammation and active lupus. Rituximab and belimumab are two such drugs that are used to treat lupus.

Rituximab works by reducing the number of certain B cells (a type of white cell) in your circulation and so decreases inflammation and therefore helps to control your disease. It is used to treat moderate and severe lupus.

Before starting the infusions, your doctor will perform a blood test to see if you have previously had hepatitis B as there is a risk of reactivation (the infection becoming active again). Rituximab is given by a drip into a vein in your arm (intravenously). The first course of treatment will usually consist of two infusions two weeks apart. Whilst the drug is being administered into the vein, you may experience an 'infusion reaction'. If this occurs you may notice that you start to shiver, develop a rash, start to wheeze or develop swelling of the lips. It is not possible to predict who will experience this side effect. If these symptoms occur, then tell the nurse/doctor immediately. The infusion will be temporarily stopped and when your symptoms have settled, the treatment can usually be restarted at a slower rate. A second course of rituximab may be given when your lupus starts to flare.

NHS England has published a drug policy statement outlining who is eligible for treatment with rituximab. A patient must have a certain level of active disease and have failed or been unable to take certain immunospuppressants such as mycophenolate or cyclophosphamide. Entry onto the lupus rituximab register (BILAG BR) is also strongly recommended as we need to continue to obtain data about the effects (benefits as well as potential side effects) of this drug.

Belimumab works by blocking the attachment of an activating factor onto the surface of B cells. Belimumab is licensed to treat arthritis and rashes in patients with lupus. It is given every four weeks intravenously. The use of belimumab has now been approved by NICE (the National Institute for Health and Care Excellence). NICE has published a guideline that details which patients can receive this drug. A patient must have high lupus activity despite standard therapy with immunosuppressants and positive antibodies.

Other drugs

Intravenous immunoglobulin (IVIg) may be occasionally used to treat low platelets in patients with lupus. It is a blood product.

Mepacrine may be used in lupus patients with rashes who have not responded to hydroxychloroquine or are unable to tolerate hydroxychloroquine. It may turn the skin slightly yellow.

Non-lupus drugs

Various medications have helped to improve the long term outcome of patients with lupus, such as tablets to control blood pressure, and anticoagulants (aspirin or warfarin) in those patients with an increased risk of developing blood clots. Patients who take long-term steroids are at an increased risk of osteoporosis, so calcium and vitamin D3 preparations are usually prescribed when a patient starts prednisolone. Other drugs for the prevention and treatment of osteoporotic fractures may be advised in those not planning a pregnancy (e.g. bisphosphonates such as alendronic acid or risedronate).

HRT (hormone replacement therapy) and the Contraceptive

Pill. It is recognised that those women with severe lupus and/or antiphospholipid antibodies are at an increased risk of thrombosis (clots) or migraine when taking contraception containing oestrogen, so progesterone-only contraception may be advised. Hormone replacement therapy containing oestrogen for post-menopausal lupus patients is not recommended for long term use as it may cause an increased risk of heart attacks.

Anticoagulants are generally prescribed for patients with the blood clotting disorder APS, (Antiphospholipid syndrome) which can be a primary diagnosis or secondary to lupus. For further information on these drugs go to www.aps-support.org.uk/about-aps/anticoagulants.php

Complementary/alternative therapies
We are aware that many people want to try complementary therapies for the relief of symptoms but we recommend that you tell your rheumatology team who will support and advise you. Remember even if something says "natural" or "herbal" they still may have an interaction with your prescribed medication.

Sun block

Sunlight can cause a flare of lupus. Exposure to ultraviolet light particularly can cause some lupus rashes. Patients with lupus are therefore advised to avoid exposure to sunlight for prolonged periods and to apply a high factor sun block with both UVA and UVB protection regularly.

Taking your medication

In order for a medicine to be effective it must reach a particular concentration in the blood and/or tissues, e.g. skin, joints, kidneys, and therefore it is important to take a medicine regularly, at the prescribed dose and frequency in order to reach and maintain this “effective concentration”.

For people with chronic diseases, such as lupus, it is tempting to give up on medicine if the hoped for benefits are not seen quickly, but it is best to be patient and to persevere according to the prescriber’s advice. All the immunosuppressants used to treat lupus can take several weeks to become effective. Drugs should not be stopped just because you feel better, as many drugs are used to help prevent problems in the future, as well as to treat current symptoms. It can sometimes be hard to distinguish symptoms of the disease from side-effects of the drug, so always reduce drugs as recommended by your doctor or nurse and discuss any concerns that you might have before changing your treatment.

Anyone who is unclear, concerned or dissatisfied with any aspect of their medication, including meeting the cost of drugs prescribed for them, should always discuss this with their doctor, nurse or pharmacist.

Information about help with prescription charges can be found at: **www.lupusuk.org.uk/prescription-charges.**

The LUPUS UK Range of Factsheets

A range of factsheets is available as follows:

1. **LUPUS Incidence within the Community**
2. **LUPUS A Guide for Patients**
3. **LUPUS The Symptoms and Diagnosis**
4. **LUPUS The Joints and Muscles**
5. **LUPUS The Skin and Hair**
6. **LUPUS Fatigue and your Lifestyle**
7. **LUPUS and Pregnancy**
8. **LUPUS and Blood Disorders**
9. **LUPUS and Medication**
10. **LUPUS and the Kidneys**
11. **LUPUS and Associated Conditions**
12. **LUPUS and the Brain**
13. **LUPUS The Heart and Lungs**
14. **LUPUS The Mouth, Nose and Eyes**
15. **LUPUS and Light Sensitivity**
16. **LUPUS and the Feet**
17. **LUPUS and Men**
18. **LUPUS and Mixed Connective Tissue Disease**
19. **LUPUS Bone Health and Osteoporosis**

LUPUS UK is the registered national charity caring for people with lupus and has over 5,000 members who are supported by the Regional Groups.

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Please contact our National Office should you require further information about the sources used in the production of this factsheet or for further information about lupus. LUPUS UK will be pleased to provide a booklist and details of membership.

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