NUHS
National University
Health System

Patient and Family Information Leaflet

Systemic Lupus Erythematosus

What is Systemic Lupus Erythematosus (SLE)?

SLE (also known as ‘Lupus’) is a chronic autoimmune disease that occurs when the body's immune system (which usually protects the body from infections) attacks its own tissues and organs. It occurs more frequently in younger women in their childbearing years. Inflammation caused by lupus can affect many different body systems, including the joints, skin, kidneys, blood cells, heart, lungs and brain. It can range from mild to severe disease. Symptoms may come and go, resulting in disease flares and periods of remission.

What causes SLE?

The exact cause of SLE is not fully understood, but it is thought to be contributed by a complex relationship between genetic, hormonal and environmental factors.

- Genetics: A family history of lupus or other autoimmune diseases can raise your risk. Studies have also demonstrated to a higher prevalence, increased severity and earlier onset of the disease due to Asian-specific genetic factors.
- Hormones: SLE is more common in women, especially during childbearing years, suggesting that oestrogen may play a role.
- Environmental triggers: sunlight (UV exposure), infections, certain medications, and stress can sometimes trigger lupus flares.

What are the symptoms of SLE?

Symptoms can vary depending on which organ system is affected and the severity of involvement. Signs and symptoms often develop gradually but may come on suddenly.

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Some common symptoms may include:

- Fatigue
- Persistent fever
- Joint pain, stiffness and swelling
- Weight loss or gain
- Skin lesions/rashes that appear or worsen with sun exposure
- Butterfly-shaped rash (malar rash) on the face that covers the cheeks and bridge of the nose
- Mouth ulcers
- Hair loss (alopecia)
- Fingers and toes that turn white or blue when exposed to cold or during stressful periods (Raynaud's phenomenon)
- Shortness of breath
- Chest pain worse with taking deep breaths
- Leg swelling and bubbles in the urine
- Dry eyes or mouth
- Easy bruising
- Fits (seizures), paralysis, memory loss, confusion

Not everyone will experience all these symptoms. These symptoms may improve with adequate treatment and recur during disease flares.

How is SLE diagnosed?

Diagnosing lupus is difficult because signs and symptoms vary considerably from person to person. Symptoms may vary in severity and may change over time. Symptoms of SLE may also overlap with those of many other disorders. Furthermore, there is no single test for diagnosing SLE.

Diagnosis usually involves a combination of:

- Detailed medical history and physical examination
- Blood tests including blood counts, kidney, liver tests, inflammatory markers, and antibody tests such as the anti-nuclear antibody, anti-double stranded DNA, anti-Smith,

anti-Ro/La, complements (a type of protein) and other autoimmune markers
- Urine tests to check for kidney involvement
- Imaging tests like X-rays / ultrasound scans / CT scan depending on the suspected organ involvement
- Biopsy (taking a sample of tissue for examination under the microscope) may be done for certain patients e.g. kidney / skin biopsy

What is the treatment of SLE?

SLE is a chronic condition that can be managed effectively with medications. With treatment, most people with lupus can lead active lives.

Hydroxychloroquine (HCQ) is a key medication that has been shown to have benefit in reducing disease flares, improving lifespan, preventing blood clots, and lowering cholesterol in SLE patients. Side effects are generally mild, and most patients are able to take it without problems. Regular eye screening by an ophthalmologist is recommended while on the medication.

However, hydroxychloroquine alone may be insufficient in severe disease and stronger medications may be required:

- **Steroids (corticosteroids)** are strong immune suppression medications that work quickly to calm down the overactive immune system. They may be given through the veins (intravenous) in severe disease or as oral tablets. Steroid creams may be given in patients with rashes due to lupus. Steroids may also be given through injections into a swollen joint to reduce inflammation in a more directed manner.

- **Immunosuppressants** may be given to reduce the need for long-term steroids for patients with more severe organ involvement. These may be in the form of tablets (e.g. mycophenolate mofetil, mycophenolic sodium, azathioprine, ciclosporin, tacrolimus, methotrexate) or intravenous infusions through the veins (e.g. cyclophosphamide). The choice of immunosuppressants depends on the affected parts of the body and severity of involvement. Blood tests monitoring is usually required while on these medications.

- **Biologic medications** are newer medications that treat SLE in a more targeted manner. They are often given through intravenous infusions (e.g. belimumab, rituximab).

Higher doses of medications are often required initially during disease flares, and doses will be reduced when SLE is controlled.

Other supportive medications may be started in addition to immune suppressing medications. Non-steroidal anti-inflammatory drugs (NSAIDs) may be given for inflammation affecting the joints or lining of the heart / lungs. Other medications such as blood thinning medication (aspirin or warfarin) and blood pressure medications may be required for certain patients.

To prevent infections when on high doses of immune suppression medications, prophylactic antibiotics and certain vaccinations are encouraged (e.g. influenza, pneumococcal, COVID-19, shingles and HPV vaccine).

As several organ systems may be affected in the same patient, SLE patients are often managed by a team of medical professionals from different specialties in a coordinated manner. Your treatment plan will be tailored to your symptoms and preferences.

What should I do if I have SLE?

Patients with SLE can live active lives with the right treatment and support. Some recommended lifestyle changes include:

- **Avoid excessive sun exposure as UV rays can trigger SLE flares. Use sunscreen daily** (at least SPF 50) and wear protective clothing.
- **Eat a balanced diet**. Avoid raw and partially cooked food to reduce risks of infections, especially if you are on steroids or immunosuppressants.
- Avoid smoking.
- **Stay active and exercise in moderation**. Ensure sufficient rest and sleep well.
- If you have Raynaud's phenomenon: keep core body and digits warm in cold temperatures
- **Attend regular medical check-ups** to monitor your health. Participate actively in your care and ask questions during your clinic consultations.
- **Take your medications as prescribed**, even when you feel well to avoid disease flares.
- **Reach out for support** – whether through friends, family, or lupus support groups such as the **Lupus Association Singapore**

Can patients with SLE have children?

This is a common concern amongst SLE patients as the disease often affects women of childbearing age. Patients with SLE can have successful pregnancies if their disease is well controlled. Pregnancy plans should be deferred in active or recent disease flares to reduce risks of complications. Some medications are not suitable for pregnancy and will need to be switched prior to conception. Patient with certain antibodies may require additional monitoring and medications during pregnancy. Hence, it is crucial to have family planning discussions early.

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Notes:

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