Systemic Lupus Erthymatosus  
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Systemic Lupus Erthymatosus (SLE), or more commonly called ‘lupus’, is at present an incurable illness of the immune system, a condition in which the body’s defence mechanism begins to attack itself through an excess of antibodies in the blood stream, causing inflammation and damage to joints, muscles and other organs.

The majority of lupus patients are female, but men and young children can be affected. It is estimated that as many as 1 in 750 women suffer with lupus in the UK, with the ratio of women to men 9:1.

The disease may be triggered by various means and can present in a bewildering number of ways, even to the extent of mimicking other diseases, such as rheumatoid arthritis or multiple sclerosis. The cause of lupus is not positively known, but research is providing evidence suggesting heredity, hormones and infections including viruses. The list below is thought to be the main triggers:

- Puberty
- Menopause
- Stress and trauma
- Childbirth
- Viral infection
- Sunlight

Lupus is also often triggered in people where there is existing family history of immune system illnesses.

Although there are many possible manifestations of lupus, those listed below are some of the more common. Rarely do two people have exactly the same symptoms, and these can vary from just one to many:

- Joint and muscle pain
- Kidney problems
- Oral/nasal ulcers
- Flu like symptoms
- Poor circulation
- Seizures/Cerebral problems
- Rashes over checks
- Extreme fatigue
- Miscarriages
- Inflammation of tissue covering internal organs
- Anaemia
- Headaches/Migraines

A person with lupus, may have four or five of the above symptoms, some of these might recede, and/or others develop.

With its many symptoms lupus can often be overlooked by a GP or consultant. This may delay final diagnosis and a vital start to necessary treatment to contain the disease and limit damage to the kidneys, heart, lungs or brain. Those diagnosed usually remain in medical care and receive ongoing treatment for life.
The diagnosis of lupus is usually on clinical grounds. The combinations of the features described above, sometimes but not always, make the diagnosis clear. Unfortunately in many patients, especially those who do not have classical tell tale signs, the diagnosis is missed, and it’s not unusual for people to wait over five years for a firm diagnosis, and often they are the wrong diagnosis such as ME of multiple sclerosis. Diagnosis is critical in any individual where lupus is suspected.

Lupus is now invariably diagnosed by blood tests, these include:

Antinuclear antibody (ANA) – a cheap and reproducible test, it’s the ‘screening test’ for lupus, being positive in over 90% of cases. It is not specific for lupus but because of its simplicity it is a useful first step in diagnosis.

DNA antibodies - this is the highly specific test for lupus. For some unknown reason the presence of antibodies against double-stranded DNA is the hallmark of lupus.

Antiphospholid antibodies - these tests are associated with the important problem of ‘sticky blood’. Patients with high levels of antiphospholid antibodies have an increased tendency to clotting in the veins and arteries and in pregnant women there is a risk of thrombosis in the placenta leading to miscarriage.

Along with the above, urine tests are carried out. This simple test uses a ‘dipstick’ to check for protein, often the earliest signs of kidney disease.

More complicated tests are carried out when necessary, such as echocardiograms, kidneys scans etc.

The treatment for lupus usually means a lifetime of medication, the list below are some of the more common drugs used to bring the disease under control:

Non Steroidals – anti-inflammatory drugs (NSAIDS), used for patients who suffer mainly from joint/muscle pain, Heparin or warfarin may be prescribed in the case of patients needing anticoagulation treatment.

Anti-Malarials – these are of help in patients with skin and joint involvement. The drugs may be sufficient for patients with moderately active lupus to avoid using steroids. Hydroxychloroquine and mepacrine are most commonly used.

Steroids - such as prednisolone, these have proved vital in the improvement of lupus care and in some cases are life saving. They have a profound effect on inflammation and suppress active disease. The dosage depends on the severity
of the symptoms. Once the disease is under control the patient is transferred to other medication.

Immunosuppressants – these drugs are widely used in more severe disease. The most commonly used are azathioprine, methotrexate (but only as a last resort these days because of the side affects), cyclophosphamide. Regular blood testing is required initially 2-3 weekly, and then 4-6 weekly whilst on such medication.

Today doctors are becoming much more aware of the side affects of drugs, and will usually only keep the patient on high impact medication for as short a period as possible.

There is at present no cure for lupus, but careful monitoring of the disease and a making the necessary adjustments to lifestyle, including a healthy diet, gentle exercise, such as Tai Chi or Yoga, and recognising when rest is needed, most patients are able to live a normal life span.

Lupus was once described as “Having your mind in fifth gear and not being able to get your body out of first.”

Linda’s story

I was first diagnosed with lupus 23 years ago, after the birth of my second son. My story will be familiar to many people who have Lupus. Around the age of 13 years (puberty), I started to have very painful joints, especially knees; these would swell and feel very hot. My family doctor at that time, diagnosed ‘growing pains’ and assured my parents that the symptoms would vanish within a few months. (I still have these symptoms today!!). I also started to develop frequent sore throats and very high fevers. I was referred to a consultant at St Thomas’ Hospital, London, who thought, although the tests were never conclusive, that I had Rheumatic Fever and recommended bed rest for several months, not an easy thing to do when you are a teenager wanting to enjoy life. Eventually I began to feel better, although the joint pains never really disappeared for very long.

During my late teens and earlier twenties, I felt very well, but seemed to have more coughs and cold than my friends.

At the age of twenty-six I married and became pregnant. The pregnancy was not a pleasant experience. Being constantly sick and losing weight, I spent long periods in hospital with no real explanation given as to why I should feel so ill. Dominic was born three weeks early, but was, thankfully a healthy 7lb 7oz baby.
Returning home after the birth, I was constantly tired and seemed to have no energy to enjoy being a mother, everything was an effort and I began to feel very guilty, I was sure my family and friends thought I was lazy. This turned out not be true, infact they were very concerned for me.

Three years later I was pregnant again. This time the pregnancy was good, no sickness and for the first time for many years, I felt well. Once again the baby was born strong and healthy, however my energy once more plummeted, and I began to feel unwell.

No one could explain what was happening to me, I had repeated colds, and very painful joints, and soon I began to get repeated bouts of pleurisy which antibiotics had no effect on. I seemed to be constantly in the GP’s surgery, who more or less hinted (and he wasn’t the only medical doctor to do so) that I was a hypochondriac. After a really bad cold had turned into pneumonia, I was referred to the Brompton Hospital in London, where I spent 4 weeks undergoing tests until a firm diagnosis of Lupus was found. This was a horrendous time, some 150 miles away from home and my small baby and 3 year old son.

I, and no one else it seemed, had never heard of SLE. The consultant at the Brompton explained that the outlook could be very bleak. There was no cure for lupus and my life expectancy could be very much shortened.

The treatment to help bring the symptoms under control was frightening: steroids, long term antibiotics, ventolin by mouth, ventolin by inhaler, chloroquin to help fatigue and joint pain as well as nose drops etc. I left hospital with a carrier bag full of drugs.

After a year of this treatment, I suddenly realised I did not feel in control of the way I felt, or indeed my life. I could not distinguish the Lupus symptoms from the side effects of the medication. I always felt sluggish, the energy had not improved.

I began to search for natural remedies and treatments that might help in some way, and as I was frightened, it was important that these should work along side the medication and not in place of.

I became a vegetarian and tried to eat healthily, using local organic products where possible, this in itself helped me feel quite a lot better, I took gently exercise, took various vitamins and mineral, and began my search for a gentle hands-on therapy.

I found Reflexology.

At first this was a very painful treatment to have, it seemed every part of my feet hurt. The practitioner must have been really fed up with me pulling my feet away and complaining. After the first treatment I had no energy at all, and every joint and muscle seemed to ache. But somehow the next day I felt more positive and alive. I persevered with weekly treatments, and after about six weeks slowly began to feel much better, the feet were not so painful and my joint pain began to improve.

During this time, I was still visiting the Brompton Hospital once a month, but slowly over a period of time the tests improved and the medication was cut down.
Today some twenty years on, I still have reflexology treatments once a fortnight from a colleague, and the only medication I take is an occasional course of Hydroxichloroquin to help with pain and fatigue, this usually happens if I get a cold or infection.

Eleven years ago I qualified as a Reflexologist with the IIR, and have never looked back.

It is hard to say if there is a particular gland, organ or muscle area in the foot to suggest that a Reflexologist can work to help, as it is a multi-symptom disease. What works for one person with lupus will probably not work for another, but I strongly believe that a light, gentle treatment every one to two weeks helps to balance and keep the body working to its maximum. Regular reflexology may highlight any changes which may indicate a Lupus flare-up, so that these can be addressed quickly. Add to all of this the ‘feel good’ factor, and a more positive attitude, enabling people with Lupus to take control and fight the disease.

Systemic Lupus Erythematosus
“Hard to say – Harder to live with”

To find out more about Lupus, visit the Lupus UK website at www.lupusuk.org.uk and www.medical.lupusuk.org.uk