

## 什么是狼疮?

狼疮是当您的身体的免疫系统攻击您自己的组织和器官时而产生的一种慢性风湿疾病。狼疮造成的炎症可能影响身体许多不同的系统,包括您的关节,皮肤、肾脏、血细胞、心脏、肺和肠脏。

在正常情况下,身体的免疫系统保护身体免受[外来]侵略者如病毒、细菌和寄生虫的侵害。在狼疮中,免疫系统出现问题或{错乱}并且产生抗体攻击自身的器官-因此狼疮被认为是{自身免疫性}疾病。狼疮的病因仍然不明,但是发病一般是由多种因素例如阳光、压力或者感染等而诱发。狼疮偶尔会于家族流传。

## 谁会患上狼疮?

妇女比男性较容易患上狼疮,但原因仍然不明。亚洲人和美国黑人比白种人更易患上狼疮而且病情也比较严重。狼疮存在四个类型 -

1. 系统性红狼疮(SLE) - 全身性和最常见的类型
2. 盘状红斑狼疮 - 纯皮肤受累形式
3. 药物性狼疮 - 药物引致的狼疮
4. 新生儿狼疮 - 患SLE母亲诞下患狼疮的新生儿

狼疮的诊断和治疗在过去几年获大大改善。若能及早诊断和治疗,多数狼疮患者仍旧可以正常地生活。

## 狼疮的征兆和症状是什么?

没有两个狼疮的病例是相同的。征兆和症状也许为突发或逐渐形成,也许轻微或严重,病情也许暂时或永久。多数狼疮患者都会有复发的经验 - 称为发作 - 恶化的征兆和症状于治疗后改善甚至一度完全地消失。发病过程变化莫测,因此必需长期接受治疗和复诊。

狼疮的征兆和症状将取決于身体哪些系统受疾病所影响。一般来说,SLE的征兆和症状包括以下:-

- 发热、疲劳和体重下降
- 关节痛、僵硬和肿胀,扩散性肌肉疼痛
- 蝴蝶型皮疹覆盖于面颊和鼻梁,并於太阳暴晒下恶化
- 脱发、口腔溃疡和容易瘀伤
- 呼吸时胸痛、气促

- 眼皮附近、双足及双脚肿胀,排尿变少
- 偶然当狼疮影响神经系统时,患者可能会出现头疼、记忆力变化、意识障碍,昏睡、精神病、中风、瘫痪、痉挛、肌肉无力和昏迷

## 怎样诊断狼疮?

诊断狼疮是困难的,因为疾病因人而异,征兆和症状的来去变化莫测,并且与许多其它疾病相同。因此,在症状变得更明显之前,医生可能不会将之诊断为狼疮。即使诊断为狼疮,在免受质疑的情况下,仍需要进行一定数量的测试以确认诊断。这些测试包括以下:

- **血液常规检查** - 这个测试测量您的血红蛋白,红细胞、白血球和血小板的数量。结果也许显示您有贫血症、低白血球或者低血小板数量。这些都是狼疮中常见的症状。过低的血小板数量可能导致自发性的皮下出血(瘀青)、胃出血甚至脑出血。
- **ESR或红细胞沉降率** - ESR度数在许多疾病包括狼疮中都会上升。所以一般用以监察疾病活动。当您的病情改进后,您的ESR亦会同时下降。
- **尿液测试** - 如果狼疮已影响至肾脏,您的尿液测试样本便可能会显示红细胞或蛋白质水平的增长。
- **肾功能测试** - 以验血评估您的肾功能状况。
- **抗核抗体(ANA)测试** - 测试结果为阳性表示您体内的免疫系统因受刺激而产生抗体,这些抗体在狼疮和其它自身免疫性疾病中都会出现。然而测试结果为阳性也不代表您患上狼疮,因为某些感染或药物都会产生阳性效果。事实上,大约5-8%正常人都可能有轻微上升的ANA,所以这个测试需要与病历和身体检查一起诠释。
- **抗双链DNA抗体测试** - 这个测试经常与ANA测试一同使用。患有狼疮并肾脏受累的患者,经常有抗双链DNA抗体测试上升的情况。

## 怎样治疗狼疮?

狼疮没有标准的治疗方法。治疗取決于征兆和症状及受累的器官。在决定药物疗程前应先与您的医生仔细地讨论其效益和风险。在最初为了迅速控制您的病情及预防永久残损,您的医生也许会推荐大剂量及特强的药物。但是当病情受控后,便会仔细地逐渐减轻药物剂量。侵略性的狼疮一般需要更加强力的药物。

在首次诊断为狼疮后,您的医生在一般情况下会推荐以下药物:

- **非类固醇抗炎药(NSAIDs)**  
包括diclofenac acid(服他宁)和更新的环氧化酶-2抑制剂(celebrex和Arcoxia)。它们能有效地控制发热、肌肉疼痛,关节痛和肿胀。
- **抗疟疾药物**  
疟疾和狼疮之间没有已知的关系,这种药物已证明了对病情轻微及皮肤受累的狼疮患者特别有用。Hydroxychloroquine (Plaquenil)是通常使用的抗疟疾药物。
- **皮质类固醇**  
这种药物能有效抵抗狼疮炎症。可惜持续使用会有严重副作用,包括体重增加,容易瘀伤,高血压、糖尿病、薄骨(骨质疏松症)和增加受感染的风险。但为了防止并发肾衰竭甚至死亡,医生在没有选择的情况下便需要处方此类药物。为减少副作用,您的医生会设法将控制疾病的药量调降至最低及使用最短的时间。
- **霉酚酸脂(骁悉)**  
这是一种已被证明对某几类型狼疮有功效的新药物。它比类固醇有较少副作用,但仍缺乏长期使用的临床经验。
- **免疫抑制药**  
这种药物能压制免疫系统,对肾脏或脑部受累的严重狼疮病例尤其见效。最常用的是环磷酰胺和咪唑硫嘌呤。环磷酰胺一般通过静脉注射。其副作用包括增加感染风险、低白血球数、肝损伤及不育。这种药物需在类风湿病专家或肾病医生(肾科专家)监察下使用。

### 调整生活方式

- 调整生活方式以减少复发机会。
- 充分休息及睡眠。
- 对阳光保持警觉 - 避免日光浴及於早上10:00至下午4:00太阳最猛烈时候接触阳光。使用防晒油并穿戴防护衣物。
- 定时运动,但不宜操劳。
- 健康饮食。
- 不要吸烟并且避免摄取过量酒精。

### 怀孕和狼疮

不久以前,医生一般建议狼疮患者避孕。随着现在更加有效的治疗,狼疮患者怀孕已不再是问题。对于病情轻微的狼疮患者,怀孕一般是安全的。病情严重的狼疮患者则应避免于疾病的活跃阶段期怀孕。在开始怀孕之前,应先与您的医生相谈这个问题。如果您打算怀孕,应避免服用可能对胎儿造成损害的药物。

### 新生儿的狼疮(新生儿婴孩的狼疮)

母亲患有狼疮而将狼疮传给婴孩的情况是非常罕见的,而且一般情况都属良性。婴孩面部会出现疹并在几星期内消退。极少数婴孩会出现心率不整而需要心脏科医生的治疗。

最有效的治疗是由科风湿病医生、产科医生和儿科医生会诊。

### 应对和支持

要应付狼疮,压力不少。患上狼疮会令人忧虑、沮丧及消沉。要帮助您应付狼疮,尝试

- 认识狼疮
- 从家人和朋友之间寻求支持
- 与其他狼疮患者联系

## 结语

狼疮不是一种单一疾病-它是疾病系谱。病情可以是非常轻微但亦可以致命。诊断患上狼疮并不是遇上浩劫或被判死刑。现今已有许多有效的治疗方法。

与其它许多病症一样,早期诊断和治疗尤为重要。千万不要擅自停药或减药,在尝试新的药物前应该先知会您的医生。就如其它慢性疾病如高血压及糖尿病,您将需要接受长时期的观察及疗程。然而,一旦您的急性症状得以控制,经适量的调节,您便能如常工作及重拾您之前的生活模式。

与您的医生和护士建立良好的合作伙伴关系,并且通过积极参与有关狼疮的演讲和研讨会,以获得更多有关的资讯及最新发展。经常保持正面观点和态度。

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**National Arthritis Foundation**  
Awareness Programme

**Systemic Lupus Erythematosus**  
狼疮

## What is Systemic Lupus Erythematosus (SLE)?

Lupus is a chronic inflammatory disease that occurs when your body's immune system attacks your own tissues and organs. Inflammation caused by Lupus can affect many different body systems; including your joints, skin, kidneys, blood cells, brain, heart, lungs and intestines.

Under normal circumstances, the body's immune system protects the body against “**foreign**” invaders like viruses, bacteria and parasites. In Lupus, the immune system goes awry or “**crazy**” and produces antibodies which attack its own organs – hence Lupus is known as an “**auto-immune**” disease. The reason why this happens is not known but Lupus attacks are commonly triggered by a combination of factors such as exposure to sunlight, stress or infection. There is also a genetic factor in Lupus since occasionally Lupus runs in families.

## Who gets Lupus?

Lupus occurs more frequently in women than in men, but the reason is not clear. Asians and Afro-Americans are more prone to develop Lupus than Caucasians and the disease is more severe in these races.

- Systemic lupus erythematosus (SLE)** – the generalized form and commonest
- Discoid lupus erythematosus** – the purely skin form
- Drug-induced lupus** – lupus caused by drugs
- Neonatal lupus** – lupus in babies born to mothers with SLE

The outlook for people with Lupus was once grim, but diagnosis and treatment of the disease has improved tremendously in the last few years. With early diagnosis and treatment, most people with Lupus can lead active lives.

## What are the signs and symptoms of Lupus?

No two cases of Lupus are exactly alike. Signs and symptoms may come on suddenly or develop slowly, may be mild or severe and may be temporary or permanent. Most people with Lupus experience episodes – called “**flares**” – of worsening signs and symptoms that eventually improve or even disappear completely for a time with treatment. The disease course is unpredictable, hence long term treatment and follow-up is essential.

The signs and symptoms of Lupus will depend on which body systems are affected by the disease. In general, SLE signs and symptoms include the following:

- Fever, fatigue and weight loss.
- Joint pain, stiffness and swelling. Diffuse muscle ache.
- Butterfly-shaped rash on the face that covers the cheeks and bridge of the nose and worsens on sun-exposure.
- Hair loss, mouth ulcers and easy bruising.
- Chest pain on breathing, shortness of breath.
- Swelling around the eye-lids, swelling of the feet and legs and decrease in urine output.
- Rarely when lupus affects the nervous system, patients can present with headache, memory change, disturbance of consciousness, drowsiness, psychosis, strokes, paralysis, fits, muscle weakness and coma.

## How is Lupus diagnosed?

Diagnosing Lupus is difficult because the disease varies considerably from person to person and the signs and symptoms come and go unpredictably, and they overlap with many other diseases. For these reasons, doctors may not initially consider Lupus until the signs and symptoms become more obvious. Even then diagnosis can often be challenging and a number of laboratory tests are necessary to confirm the diagnosis. These tests include the following:

- **Complete Blood Count** – This test measures your haemoglobin, number of red blood cells, white blood cells and platelets. Results may indicate you have anaemia, low white blood cell or platelet count. This often occurs in Lupus. An extremely low platelet count can result in spontaneous bleeding in the skin (bruises), in the stomach or even in the brain.
- **ESR or Erythrocyte Sedimentation Rate** - ESR is raised in many diseases including Lupus. It is in general a good measure of disease activity and as your disease improved your ESR drops.
- **Urine Examination** – An examination of your urine may show an increase in red blood cells or protein level. This can occur if your Lupus has affected your kidneys.
- **Kidney Function Test** – Blood tests can assess how well your kidneys are functioning.
- **Antinuclear Antibody (ANA) Test** – A positive test for the presence of these antibodies produced by your own immune system indicates a stimulated immune system

which is common in Lupus and other autoimmune diseases. However, a positive ANA test does not always indicate you have Lupus since certain infections or drugs can also cause a positive test. In fact, about 5-8% of normal people can have a slightly raised ANA antibody test. Therefore this test needs to be interpreted in conjunction with a proper history and physical examination.

- **Anti-dsDNA Test** – This test is often done together with the ANA test. Patients with Lupus and kidney involvement often have a raised Anit-dsDNA test.

## How is Lupus treated?

There is no standard treatment for Lupus. Treatment depends on your signs and symptoms and which organs are involved. Determining what medications to use requires a careful discussion of the benefits and risks with your doctor. In order to control your disease quickly before permanent damage is done, your doctor may recommend more powerful drugs in higher doses initially but as the disease severity subsides the dosage can usually be tapered off slowly and carefully. More aggressive Lupus usually requires more powerful drugs. In general, when first diagnosed with Lupus, your doctor may recommend the following medications:

- **Non-Steroidal Anti-Inflammatory Drugs (NSAIDs)**  
These include Diclofenac Acid (*Voltaren*) and the newer COX 2 inhibitors (Celebrex and Arcoxia). They are effective in controlling fever, muscle aches, joint pains and swelling.
- **Antimalarial Drugs**  
Although there is no known relationship between Malaria and Lupus, these medications have proved useful especially in patients with mild Lupus and those with skin involvement. Hydroxychloroquine (*Plaquenil*) is the most commonly prescribed Antimalarial Drug.
- **Corticosteroids**  
These drugs counter the inflammation of Lupus and are very effective. Unfortunately, they can have serious long term sideeffects including weight gain, easy bruising, high blood pressure, diabetes, thinning bones (**Osteoporosis**) and increase risk of infection. Very often doctors have no choice but to prescribe such drugs in order to prevent permanent damage like kidney failure or even death. To help reduce the side-effects, your doctor will try to find the lowest dose that controls the disease and prescribe the medicine for the shortest possible time.

- **Mycophenolate Mofetil (Cellcept)**  
This is a new drug which has proven to be useful in certain types of Lupus. They have less side-effects than steroids but long term experience is still lacking.
- **Immunosuppressive Drugs**  
These drugs suppress the immune system and may be useful in serious cases of Lupus like those with severe kidney or brain involvement. The most commonly used are cyclophosphamide and Azathioprine. Cyclophosphamide is often given by injecting into the veins. Side-effects include an increased risk of infection, low white cell count, liver damage and infertility. These drugs should only be used under close supervision by a Rheumatologist or a Nephrologist (Kidney Specialist).

## Lifestyle Changes

Lifestyle changes are needed to reduce the incidence of relapses.

- Get adequate rest and sleep
- Be sun smart – avoid sun-bathing and stay out of the sun entirely when it is the strongest between 10am – 4pm. Use sunblock creams and wear protective clothing.
- Get regular exercise but do not overstrain your body
- Eat a healthy diet
- Do not smoke and avoid excessive alcohol intake

## Special problems in Lupus patients

### **Pregnancy and Lupus**

Not so long ago, doctors use to recommend that patients with Lupus should avoid pregnancy. This is no longer so as now, we have more effective treatment. Pregnancy is usually safe in patients with mild Lupus. In severe Lupus, pregnancy is best avoided during the active phase of the disease. Always discuss this problem with your Lupus doctor before embarking on pregnancy. Certain drugs can cause damage to the unborn foetus and are best avoided if you intend to become pregnant.

### **Neonatal Lupus (Lupus in newborn babies)**

Very rarely babies born to mothers with Lupus can develop a condition called Neonatal Lupus. In general, this is usually a benign condition and the baby will have some rash which subsides in a few weeks' time. Very occasionally, such babies

will have a disturbance in heart rate which will require treatment by a neonatal cardiologist.

To optimize care, it is best to have a team of Rheumatologist, Obstetrician and Paediatrician working together.

### **Coping and Support**

Coping with Lupus can be stressful. People with Lupus often experience anxiety depression and frustration. To help you cope with Lupus, try to:

- Learn all you can about Lupus
- Gather support among your friends and family
- Connect with others who have Lupus

## The Final Word

Lupus is not a single disease – it is a spectrum. It can be very mild or it can be life-threatening. The diagnosis of Lupus however is not a catastrophe or a death sentence. Many effective treatments are now available.

As with all illnesses, early diagnosis and treatment are important. Never stop or reduce medications on your own or try new medications without the knowledge of your doctor. As with all chronic diseases like hypertension and diabetes, you will need to be under medications and observation for long periods of time. However, once your acute symptoms are under control, you can return to your work and former life-style with minor modification.

Establish a good working relationship with your Lupus doctor and nurse and keep updating yourself or new developments of the disease by attending regular talks and seminars. Always have a positive outlook and attitude.

*For more information, visit the following websites:*

**The Lupus Association (Singapore)**

www.e-lupus.org

**The Lupus Foundation of America**

www.lupus.org

**Arthritis Foundation America**

www.arthritis.org