

# Lupus Link

## 新加坡狼疮协会刊物

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### Volunteer Day Celebration



International Volunteer Day: The Lupus Association, Singapore (LAS) President, Ms Nancy Chin (3rd from left), received the volunteer certificates of appreciation on behalf of the group from Dr Lim Suet Wun, CEO of Tan Tock Seng Hospital (centre).

### Our Heartfelt Thanks

We are grateful to Mr & Mrs William Graham for their generosity and continued support to the LAS. The Pump Room Pte Ltd donated \$62,000 through a charity golf event.



### ~ Announcement ~

We have received a wheelchair, bath chair and walker as a donation. Please contact the Lupus Association if you wish to borrow any of the items.

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## Dealing with Chronic Pain in Lupus

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### **How common is chronic pain in lupus?**

Pain is one of the most common manifestations of Systemic Lupus Erythematosus (SLE or Lupus). Up to 90% of people with Lupus will experience joint and/or muscle pain at some time in their life. At the onset, joint pain is a major complaint in more than 50% of patients.

### **What are the different causes of pain?**

Joint pain can arise from the joint itself or from structures around the joint. Conditions that involve the joint include Lupus associated arthritis (hereon referred to as "Lupus arthritis") and joint infection, while those that involve structures around the joint include bursitis/tendinitis (bursa and tendon inflammation respectively), fibromyalgia, carpal tunnel syndrome and avascular necrosis of the bone. These conditions are covered below and they can be due to Lupus, occur as a complication of Lupus treatment or not directly related but co-exist with Lupus.

### **What is Lupus arthritis?**

This is true joint inflammation. The important features are pain, swelling, warmth, and stiffness that is worse in the mornings and improves with activity. The joint involvement is usually symmetrical and often involves the fingers, wrists and knees. Often this does not lead to severe destruction of the joint. Joint deformity is uncommon and can occur due to lax joint capsules, ligaments and tendons which is termed "Jaccoud-type deformities".

### **How do we diagnose Lupus arthritis?**

A good history and physical examination by your doctor is of utmost importance. The pattern and distribution of joint involvement with other features of lupus are important clues. X-rays are often normal. Sometimes it may be difficult to differentiate from other more common causes of arthritis. Careful observation, investigations, and follow-up with the doctor are necessary.

### **What drug treatments are there for Lupus arthritis?**

Both drug and non-drug treatments are important in the management of arthritis. Drug treatment is aimed at reducing pain and stiffness, and preventing joint damage. Close supervision by your doctors is necessary to monitor for side-effects and response to treatment. Drugs used include simple pain killers (e.g. panadol), non-steroidal anti-inflammatory drugs (NSAIDS), prednisolone or hydroxychloroquine/ methotrexate. More immunosuppressive drugs (eg. azathioprine, cyclophosphamide) are usually not used solely for Lupus arthritis.

### **What non-drug treatments are there for Lupus arthritis?**

Physical therapy and occupational therapy complement drug treatment, and aim to relieve pain, reduce inflammation, and

preserve function. Physical therapy include heat/ cold application, ultrasound to relieve tenosynovitis, and exercises to improve/maintain range of motion of joints. Occupational therapy include education regarding joint rest, protection, self care and provision and instruction on use of assistive devices and splints.

### **What is bursitis/tendinitis?**

Bursa and tendon inflammation are usually due to physical trauma or overuse of a joint. Tendon inflammation can also be associated with Lupus arthritis, and occasionally can cause tendon rupture related to trauma or long-term use of steroids. Common regions affected are elbow (tennis/golfer's elbow), finger (trigger finger) and shoulder (rotator cuff tendinitis).

### **What is carpal tunnel syndrome?**

This is usually not related to Lupus, and is commonly due to repetitive strain injury (e.g. computer keyboard use) to the median nerve at the wrist. It can lead to tingling, numbness or pain typically affecting the lateral three and a half fingers. Occasionally, this may be associated with Lupus arthritis at the wrist.

### **What is avascular necrosis of the bone?**

This literally means "bone tissue death". It results from a decreased blood supply to the bone leading to weakening and collapse of the bone surface. This can lead to joint stiffness, pain and limitation of joint movement. Its exact cause is unknown but can be associated with Lupus and prolonged use of high dose steroids.

### **What is fibromyalgia and why is it important to recognize it?**

This is a non-inflammatory condition affecting soft tissues. The exact cause is unknown. Fibromyalgia can co-exist with Lupus and is characterized by widespread pain in the muscles and joints, fatigue, generalized weakness, non-restful sleep and multiple tender points on the body. Other features include headache, mood changes, difficulty in concentration, irritable bowel, and urinary urgency. It is important to differentiate this from Lupus as some of the symptoms are similar. Careful history and examination by the doctor is important as treatment can be quite different.

## 如何面对红斑狼疮病症所带来的长期疼痛

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### **红斑狼疮病症所带来的长期疼痛是否普遍?**

红斑狼疮病症所带来的长期疼痛是普遍的。超过90%红斑狼疮病患会感到关节疼痛或肌肉酸痛。除此之外，超过50%的人在患病的初步阶段也会投诉关节疼痛。

### 什么原因导致关节疼痛?

关节疼痛可能源自于关节或关节周围的结构。首先，与关节有关联的病症包括红斑狼疮关节炎 (Lupus arthritis) 和关节感染 (joint infection)。其次，与关节周围的结构有关联的病症则包括粘液囊炎或腱炎 (bursitis/tendinitis)，纤维肌痛 (fibromyalgia)，腕关节并发症 (carpal tunnel syndrome) 和骨头缺血坏死症 (avascular necrosis of the bone) 我接下来将介绍这些症状。它们可能是由红斑性狼疮所引发的，在治疗过程所产生，或是与红斑狼疮没有直接关系但与它共存的。

### 红斑狼疮关节炎指的是什么?

红斑狼疮关节炎指的是由红斑狼疮引发的关节炎。它的症状包括疼痛、浮肿、温热的感觉和肌肉僵硬。在此，稍略提肌肉僵硬的症状。病患常会觉得肌肉僵硬，尤其是在早晨时分但这通常会随着日常活动逐渐减缓。它也常常影响左右两侧的手指、手腕、膝盖。一般而言，红斑狼疮关节炎不会对关节构成严重的影响或缺陷。因关节、肌腱松弛等问题而造成缺陷的案例也并不普遍。

### 如何诊断红斑狼疮关节炎?

患者需经由医生的仔细检验关节分布，才能诊断出是否患上红斑狼疮关节炎。一般上，患者做了X光扫描后都没有什么异状。除了红斑狼疮关节炎，其他较为普遍的因素也可能引发关节疼痛。因此，有时我们难以判断及区分。这时候，需要观察及复诊。

### 如何治疗红斑狼疮关节炎?

在治疗红斑狼疮关节炎方面，药物及非药物治疗都一样重要。药物治疗主要是减轻关节疼痛、僵硬及其他症状。医生必须仔细观察患者对治疗的反应和是否有副作用等问题。使用药物包括止痛药 (Panadol)，非类固醇类消炎止痛药物 (NSAIDs)，脱氢皮质醇 (Prednisolone)，羟氯喹 (Hydroxychloroquine) 或甲氨喋呤 (methotrexate)。

许多免疫压制药 (Immunosuppressive drugs) 是有效的，但它们不是唯一治疗红斑狼疮的药物。

### 非药物治疗包括什么?

药物及非药物治疗是互补的。非药物治疗包括物理治疗 (Physical therapy) 和职业治疗 (Occupational therapy)。它们主要是舒缓疼痛、消炎及维持关节正常运作。物理治疗过程包括冰敷冷疗或热疗，运用超英波来舒缓腱鞘炎 (tenosynovitis) 及通过运动维持关节正常运作。职业治疗则是增进关于如何保护关节及自我护理的知识，教导患者如何使用辅助器材及尽量不触碰疼痛的关节，让它歇息等知识。

### 粘液囊炎 (bursitis) 指的是什么?

腱炎 (tendon inflammation) 主要由表面创伤、过度使用关节所导致。它可能与红斑性狼疮有关，偶尔会引发与表面创伤或长期使用类固醇 (steroid) 有关的肌腱撕裂。它常影响手臂，手指或肩膀。

### 腕关节并发症 (carpal tunnel syndrome) 指的是什么?

腕关节并发症 (carpal tunnel syndrome) 一般与红斑狼疮没有关联，而是由反复肌肉疼痛所导致的神经创伤。例如打字可能会引起微刺感、麻痹或疼痛。一般上，它影响外侧三个半手指头，有时甚至影响整个手。另外，它可能与红斑性狼疮导致的手腕关节炎有关。

### 骨头缺血坏死病症 (Avascular necrosis) 指的是什么?

骨头缺血坏死病症 (Avascular necrosis) 指的是骨头细胞坏死。这是因为传至骨头的血液不足造成骨头松弛，最后导致骨头表层塌陷。它可能导致僵硬、疼痛、局限关节活动范围。造成骨头缺血坏死病症的原因不详，但应该是与红斑性狼疮及长期使用高量的皮质类固醇 (steroids) 有关。



## 纤维肌痛 (fibromyalgia) 指的是什么? 为何得关注这个病症?

纤维肌痛 (fibromyalgia) 是个与软组织有关, 不会引发发炎的病症。它的原因不详且能与红斑性狼疮共存。纤维肌痛可能导致肌肉及关节极多部位疼痛, 疲乏, 普遍上的虚弱, 不能安枕入眠, 其他痛处。另外, 它也可能导致头痛、情绪变化、难专注、肠胃不好、尿急症等。纤维肌痛和红斑性狼疮有几个相同症状, 因此可能被误认成红斑性狼疮病发。医生需经仔细检验才能除去是因发炎或是红斑性狼疮病发所导致的可能性。

## Physical Therapy for Lupus 红斑狼疮物理治疗

Low Ai Ying

Physiotherapist, Singapore General Hospital

These exercises are general stretching and strengthening exercises. Please consult a physiotherapist or doctor before starting any exercise program. 以下提及的是一些基本的伸展运动和强化运动。在进行任何运动之前, 请征询治疗师或医生的意见。

### A - STRETCHING EXERCISES 伸展运动

Every exercise should be performed 10 times, each time holding for 15 seconds. 每项运动需进行10次, 每次维持15秒。

#### 1) Hand behind back stretch 背后伸展双手

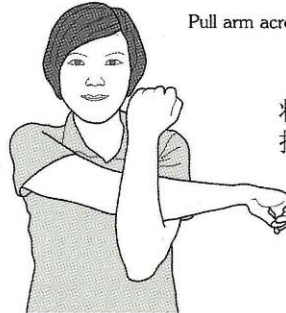


Bring right hand behind head and down as far as possible. Reach up with left hand, palm facing out, and grasp right hand.

Hold 15 seconds. May use a towel as a beginner aid to help work hands closer together. Repeat with other side.

将右手放在头后, 尽可能往下伸。手掌向外, 左手往上伸, 抓着右手。维持15秒。建议初学者使用手巾作为一种辅助, 缩短双手距离。换边重复动作。

#### 2) Posterior capsule stretch 伸展双手



Pull arm across chest until stretch is felt.

Hold for 15 seconds.

将手摆直放在胸前, 推向左边, 并伸展。维持15秒。

#### 3) Pectoralis (chest muscles) stretch 胸肌伸展



With arms forming a right angle, lean forward until stretch is felt on the chest.

Hold for 15 seconds.

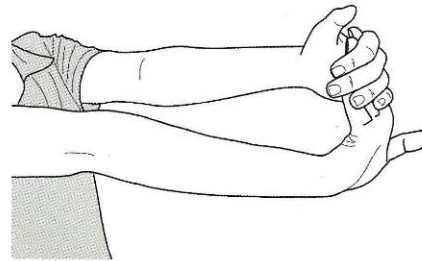
将双臂形成90度, 倾身向前, 直至伸展胸膛。维持15秒。

#### 4) Finger flexors stretch 伸展手肌

Pull fingers backwards till you feel a stretch.

Hold for 15 seconds.

将手指往内推, 直至伸展肌肉。维持15秒



#### 5) Inner thigh stretch 大腿内侧伸展



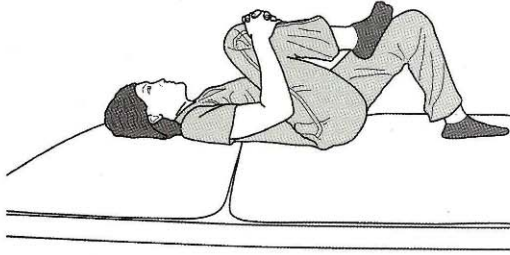
Grasping feet with hands and bending from hips, gently pull forward until stretch is felt.

Hold 15 seconds.

用手抓着双脚, 腰部向前弯, 轻轻向前拉双脚, 直到伸展肌肉。维持15秒。

### 6) Knee to chest stretch 膝盖至胸肌伸展

Bring knee to chest and hold. Hold for counts of 15.  
将膝盖放在胸前。维持15秒。



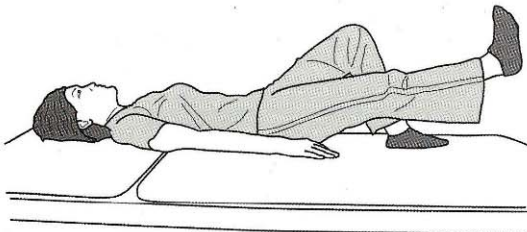
### B - STRENGTHENING EXERCISES 强化运动

Every exercise should be performed 15 times, each time holding for 10 seconds (1 set).

You should gradually work towards 3 sets of 15.  
每项运动需进行15次，每次维持10秒（1次）。

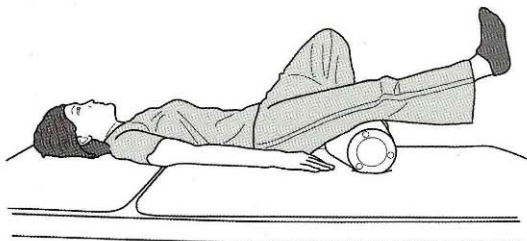
#### 1) Straight leg raise 单脚伸直

Tighten the muscles on the front of right/left thigh, and then lift leg 3-4 inches from surface, keeping knee locked. Count for 10 seconds. 紧缩左或右腿前方的肌肉，抬起脚，离地面约3到4英寸，不要弯膝盖。维持10秒。



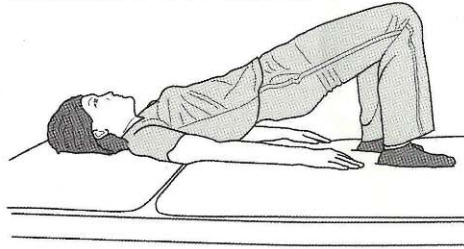
#### 2) Inner range quadriceps 四头肌内侧强化

With right/left knee over bolster, straighten knee by tightening muscles on top of thigh. Keep bottom of knee on bolster. 将左或右膝盖摆在枕垫上，紧缩大腿上边的肌肉后伸直。将膝盖底边摆在枕垫上。



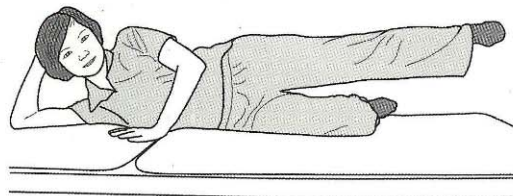
### 3) Bridging 强化

With bended knees, tighten buttock muscles and lift hip off the surface. Hold for 15 seconds. 弯着膝盖，紧缩臀部肌肉后将腰抬高离地面。维持15秒。



### 4) Hip abduction 腰部强化

Tighten muscles on front of left/right thigh, then lift leg 3-4 inches from surface, keeping knee locked. 紧缩左或右腿前方的肌肉，抬起脚，离地面约3到4英寸，不要弯膝盖。



## Thanksgiving in Struggles and Adversity by Frances Koh

One morning, 15 years ago, I awoke with a terrifying experience. Both my hands were aching and stiff, and I could not clench my fists. I felt lousy and exhausted. I spent the rest of the day in bed, thinking that I must have caught the flu bug. My friend, Kim came by in the evening and suspected that it was more serious than a bout of flu and brought me to the doctor. The doctor prescribed pain-killers and advised me to go for a blood test. The results, a few days later, suggested that I had rheumatoid arthritis. I was subsequently seen by a specialist at Tan Tock Seng Hospital, Department of Rheumatology & Immunology. Further blood tests confirmed that I have this mysterious disease called Lupus or Systemic Lupus Erythematosus. It was disheartening to learn that there is no cure for this disease and that I have to be on life-long medication.

When I was told that I had to take steroids to control the disease, I was very upset. I argued with my doctor as I did not believe that I should be put on steroids. The Rheumatology nurse, who later became a friend, impressed upon me the need to adhere to a strict medication regime so as to allow me to lead as normal a

appropriately so that I do not feel sick all the time. Without medication, sufferers of this disease may not be able to continue working and to remain active in sports which I enjoy.

Lupus is also called the disease with a thousand faces. When I get an attack, also known as a flare, my platelet counts drop, necessitating hospitalization. I have also had rashes on my face and arms, as well as a mild stroke. I continue to work part-time with a church organization and enjoy exercising and playing tennis. Every 12 weeks, I see my doctor. Blood and urine tests are done to monitor my Lupus. It is always a welcome to hear my doctor say, "The test results are okay and you are doing fine".

In early 2009, I was met with another major setback. I was diagnosed with stage 3 colon cancer. I underwent surgery and was started on chemotherapy soon after. Whilst the side effects from the Lupus medications were minor, the effects from chemotherapy were debilitating. As an example, I had such severe mouth ulcers that I could not eat. Swallowing water was a torture. Before sleeping, I would put gauze on my lips to stop any bleeding from staining the pillow. The next morning, I would forget and peel off the gauze without wetting it first. The pain was excruciating.

To add to my woes, I had to discontinue chemotherapy when I developed an allergic reaction to the drugs. My body revolted, broke into rashes and I had difficulty breathing. It was scary to learn later from my doctor that I could have been seriously ill from that episode if treatment had not been given immediately.

God has not promised to keep me free from life's storms but He has certainly given me a positive attitude. I would like to share how these words have encouraged me, "Disease has no power! It cannot cripple love, it cannot shatter hope, it cannot erode faith, it cannot eat away peace, it cannot destroy confidence, it cannot kill friendship, it cannot shut out memories, it cannot silence courage, it cannot invade the soul, it cannot take away eternal life, and it cannot quench the spirit. Our greatest enemy is not disease but despair."

Today, I am a regular volunteer at the Lupus Association, Singapore (LAS). Every Wednesday, I visit patients with Lupus who are hospitalized. The LAS is dedicated to providing practical support and friendship to patients and their families. I find it very meaningful to be able to share my experiences and lessons. Hopefully, this will allow others to understand and cope with their illness better. I would like to continue volunteering in this way till my golden years.

## 在逆境中怀有感激之心

十五年前的一个早晨，我的梦魇开始。我的双手僵硬酸痛，并且不能捏住拳头，感到很疲倦。那天，我躺在床上，心想自己感冒了，休息一会儿就好了。傍晚时分，我的朋友，Kim，来探望我。她怀疑我不仅仅是得了小感冒，就带我看医生。医生开了一些止痛药，并建议我去做血液检查。于是，我做了血液检查。几日后

，血液检查结果显示我得了风湿性关节炎。接着，我到陈笃生医院风湿免疫专科部门征询专科医生的意见。接下来的血液检查证实了我患上这个神秘的疾病：红斑狼疮（SLE）。我得知红斑狼疮病症是没有根治方法，且须长期服用治疗药物时，很是气馁。

另外，当我得知需服用类固醇（steroids）时，我很激动，与医生争论。一名护士告诉并说服我说药物治疗能令我恢复日常生活。她清楚地说明药物能助我的身体区分正常细胞和坏细胞，这样一来，我不会天天感到不适。倘若没有服用药物，患者可能无法工作或运动。当时我还不晓得，这名护士未来将成为我的朋友。

红斑狼疮也能叫做千面病毒。当病症发作时，我的血小板数量降低，就必须住院。我的脸及手臂也出疹子，而且有轻微中风。目前，我在一间基督教会兼职工作，并持续我喜爱的运动，例如打乒乓。每隔十二个星期，我就看医生，进行血液及尿液检查。每回听到医生说：“检验结果良好，你没有什么大碍”时，我就觉得很庆幸。

在2009年初，我遇到另一个挫折，也就是被诊断患上第三期结肠癌。手术后，我便开始化学治疗。这时，我才发现红斑狼疮的副作用可算是轻微的，而化学治疗带给我极多副作用。例如，我的口中长痔疮，无法吃饭。喝水也是一种折磨。此外，睡觉前，为防止嘴唇上的血迹不小心粘到枕头，我需要贴纱布。隔天，我忘了在除去纱布前需要粘点水，就直接撕开，那种痛是无法用笔墨所形容得。

更糟糕的是，我对药物敏感，而必须中断化学治疗。当时，我的身体出了大问题，到处出疹子，而且有呼吸困难。之后，医生告知我说当时，倘若我没有立刻接受治疗，很可能得重病。一想起他说的话，我就感到很害怕。

虽然上帝没承诺令风雨远离我，但他给我积极的人生观。在此，我想与大家分享以下话语：“癌病的破坏力其实非常有限：它不能侵蚀信念或粉碎希望、不能抹煞友情或令爱情变得残缺、不能封杀勇气，更无法打压回忆。它不能侵入心灵或带走永生，也不能压制心灵。我们最大的敌人不是癌病，而是绝望。”

目前，我参与狼疮协会的义务活动。每个星期三，我会探望住院的红斑狼疮病患。狼疮协会（Lupus Association）专心致志地给予病患及家属援助和友谊。我觉得能与大家分享个人经验，是很有意义的事。未来，我也会继续参与义务活动。