

Lupus Link

新加坡狼疮协会刊物

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I am honoured to be the new president of the Lupus Association of Singapore. My own journey from the time I was diagnosed with Lupus to my present state of well-being, coupled with the memory of my late sister who succumbed to the illness, has prompted me to share my experiences with fellow patients, new and existing, through LAS by reaching out to more patients so that they will not have to suffer alone, to create awareness of the disease so that Lupus patients can be better understood by their families, friends and colleagues, to help the needy

Lupus patients get the best treatments and medications possible and, of course, to widen the patient support network. I am looking forward to a happy, fruitful and enriching working relationship with those whom I am going to work closely with for the next two years.

我很荣幸能够成为新一任的狼疮协会主席。鉴于以下因素：当年患有狼疮的我如今恢复健康和因为狼疮病逝的姐姐，我想分享个人经历，以便勉励大家。大家也不必独自承受压力。另外，我希望提高狼疮的认识，这样一来，亲友同事们就能体谅狼疮病人，大家才能及早接受药物治疗。另一个目的是扩大支柱交流网。最后，我希望在未来的两年里，能与同事相处愉快。

LAS Social Friday

Dear Members

We are pleased to inform you that following your valuable feedback and suggestions, we have commenced our LAS evening gathering 'LAS Social Friday' on the 27th May 2011. It is set on the last Friday of every month. The get-together is intended for LAS members to better socialize, network, share, and in the process, support one another. We hope to see good participation and are looking forward to meeting up with all of you. We are also open to the contribution of ideas to make the gatherings more successful.

Date : Last Friday of the month

Time : 6.30 pm to 9.30 pm

Venue : TTSH Annexe Bldg. Level 1 (Balestier Room)

Please make the effort to attend so that we can get to know you!

The gathering can only be a success with your support and attendance. Let's get together and have a relaxing, fun and fruitful time. For further information, please contact Linda at tel.62549130 (LAS office) or drop us an email at: (enquiry@e-lupus.org) to confirm your attendance.

Thank you.
Irene Lim
President



Council Members

President

Irene Lim

Vice President

Dr Leong Keng Hong

Hon Secretary

Serene Mai

Hon Treasurer

Jennie Sokolik

Welfare Officer

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Eating Well with Lupus

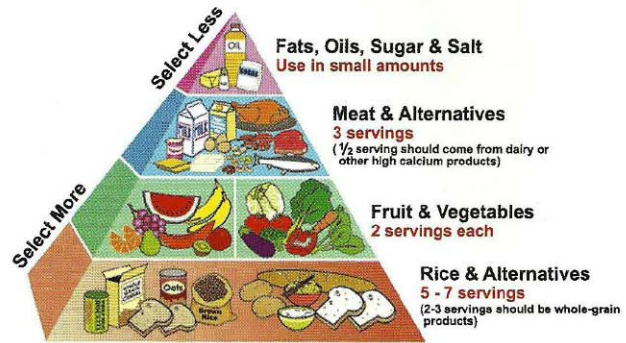
By Dietitian Khor May Jiun

Department of Dietetics & Nutrition Services

Singapore General Hospital

Although studies have suggested that some nutrients may play an important role in Lupus management, there is insufficient evidence to make any recommendations at this stage. Experts agree that a well-balanced diet offers the greatest benefits for people with Lupus regardless of the disease stage.

The Healthy Diet Pyramid is a guide to help you plan a well-balanced diet that provides the nutrients you need, in the right amounts, each day.



The Healthy Diet Pyramid for Adults

(Source: Health Promotion Board, Singapore)

Food group	Examples of one serving	Notes
Rice and Alternatives	<ul style="list-style-type: none"> ● 2 slices bread (60g) ● 1/2 bowl rice or noodles (100g) ● 1 thosai or 2 chapattis (60g) 	<ul style="list-style-type: none"> ● Aim 5-7 servings a day ● Good sources of carbohydrates (starches), dietary fibre and vitamins B and E ● Choose 2-3 servings from wholegrain products
Fruit	<ul style="list-style-type: none"> ● 1 small apple or orange (130g) ● 1 wedge papaya (130g) ● 10 grapes or longans (50g) 	<ul style="list-style-type: none"> ● Aim 2 servings a day (for each fruit and vegetables group) ● Good sources of beta-carotene, vitamin C, dietary fibre and other phytochemicals ● For fruit, choose a serve from brightly coloured fruit e.g. orange and papaya ● For vegetables, choose a serve from dark green leafy or brightly coloured vegetables such as brinjal
Vegetables	<ul style="list-style-type: none"> ● 3/4 mug* cooked vegetables (100g) ● 150g raw leafy vegetables ● 100g raw non-leafy vegetables <p>* Mugs are of 250ml capacity</p>	
Meat and Alternatives	<ul style="list-style-type: none"> ● 1 palm-sized piece fish, meat or poultry (90g) ● 3/4 cup cooked lentils, beans and peas (120g) ● 2 small blocks soft bean curd (170g) ● 2 glasses milk (500 ml) 	<ul style="list-style-type: none"> ● Aim 2-3 servings a day ● Good sources of protein, some vitamins and minerals ● Always choose lean meat, skinless poultry and lowfat or non-fat milk and dairy products ● Include 2-3 serves of oily fish a week (e.g. salmon, mackerel, and sardine) to ensure good intake of omega-3 fatty acids.

Note: Fats, oils, sugar and salt – use only small amounts

If you take steroid medication, you may need to watch your diet due to the possible side effects as follows:

Side effects of Steroid medication	Food/nutrients to note
Osteoporosis	Regular intake of calcium-rich food such as milk and dairy products, high calcium soymilk, fish with edible bones and bean products in your daily diet.
High blood sugar level	Include high fibre food (e.g. wholegrains and vegetables) and limit sugary foods in your diet.
High blood cholesterol level	Limit saturated fat intake from animal fat (skin of poultry, visible fat on meat, ghee and butter) and plant sources (palm oil and coconut milk). Also watch cholesterol-rich food.
Fluid retention	Watch your intake of salt (sodium), high sodium food e.g. processed meat and preserved vegetables
Excessive weight gain	Limit calorie dense food (particularly those high in fat and refined sugar)

Note: You may need to modify your diet if you have certain Lupus complications e.g. kidney-related conditions. It is best to seek advice from your physician and dietitian.

Food Claims – Frequently Asked Questions

1. I heard that certain food such as alfalfa sprouts could cause Lupus flares. Is that true?

There are reports which have shown that a substance in alfalfa sprouts (L-canavanine) may lead to lupus flares. Large consumption of alfalfa sprouts may not be advisable. Alfalfa sprouts supplements should be avoided.

2. Does 'anti-inflammatory' diet work for people with Lupus? How about fish oil supplement?

There is no specific 'anti-inflammatory' diet. The omega-3 fatty acids (found in food e.g. oily fish, walnuts etc.) have anti-inflammatory effects. At this stage, there is no conclusive evidence to recommend fish oil supplementation for people with Lupus. Taking 2-3 serves of oily fish per week in your diet will ensure good intake of omega-3 fatty acids.

3. Is there any specific diet and nutritional supplements that I should be taking to reduce the Lupus flares?

There is no conclusive evidence from human studies to support any specific diet or nutritional supplements which may help to reduce the Lupus flares. **The most prudent advice is to have a healthy balanced diet with plenty of fruit and vegetables, wholegrains, moderate amounts of low-fat milk and dairy products, lean meat, poultry and fish.**

健康饮食

虽然一些研究报告提出吸取特定的营养钙质有助于控制狼疮病情，可是至目前为止，仍然没有足够研究显示这的确有效。专家也同意保持饮食均衡有助于控制狼疮病情。健康饮食金字塔能辅助人们保持饮食均衡，给予每日足够的钙质和养分。(源自：新加坡卫生局和<http://www.cuhk.edu.hk/proj/growthstd/chinese/foodpyra.htm>)



食物种类	1份量	须知
米饭和其他	两片面包 (60克) 半碗饭或面 (100克)	每日5-7份量 给予碳水化合物 (淀粉类), 食物纤维素, 维生素B和E 从全麦食品选2-3份
水果	1份苹果或橙 (130克) 1份木瓜 (130克) 10颗葡萄或龙眼 (50克)	每日2份量 给予维生素C, 食物纤维素和其他钙质 请选择亮色水果, 如橙和木瓜 请选择暗绿色蔬菜或亮色蔬菜
蔬菜	¼杯煮过的蔬菜 (100克) 150克未煮过的的有叶蔬菜 100克未煮过的无叶蔬菜 1杯容纳 250毫升	每日2份量 给予维生素C, 食物纤维素和其他钙质 请选择亮色水果, 如橙和木瓜 请选择暗绿色蔬菜或亮色蔬菜
肉类和其他	1块掌心型鱼肉, 肉食或其它 (90克) ¼杯煮过的黄豆和豌豆 (120克) 2块豆腐 (170克) 2杯牛奶 (500毫升)	每日2-3份量 给予蛋白质, 维生素和矿物质 请选用瘦肉, 去皮肉类和低脂肪或无脂肪牛奶和奶制食品 一周食用2-3分量的油鱼如三文鱼, 秋刀鱼和沙丁鱼, 确保有足够的Ω-3脂肪酸 (omega-3 fatty acids)

注: 请适量食用脂肪, 油, 糖和盐

类固醇药物的副作用	需留意事项
骨质疏松症	每日食用高钙质食物如奶制食品，高钙豆奶，软骨鱼或豆制品
高血糖	食用高纤维食物（如全麦蔬菜）和控制糖制食品
高胆固醇	控制源自动物脂肪的饱和脂肪（如动物皮，肉类上的皮层，牛油）和植物脂肪（棕榈油和椰子油），同时注意高胆固醇食物
体内多余水分	注意盐量（钠），高钠食物如加工肉食和加工蔬菜
体重过度增加	控制高碳水化合物食物，尤其是高脂肪和精制糖

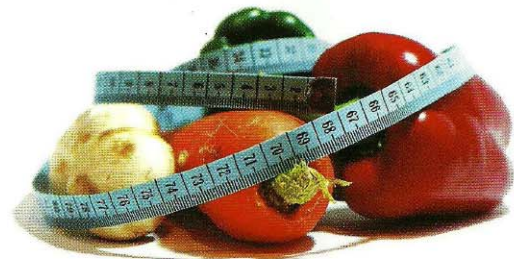
注：您或许得依据狼疮病情而调试饮食习惯如肾脏问题等。请请教医生或调养师。

饮食常见问题

1. 我听说有一些食物如豆芽菜会引起狼疮复发。这是真的吗？有报告显示，豆芽菜内含有的一种成分（L-canavanine）可能导致狼疮复发。因此，不鼓励大家大量食用豆芽菜，同时，也该避免服用豆芽菜类保健品。

2. “防止刺激性”饮食配方对于狼疮患者有效吗？此外，服用鱼油保健品有效吗？我们并没有所谓的“防止刺激性”饮食配方。鱼油和胡桃仁中所含的 Ω -3脂肪酸（omega-3 fatty acids）是有防止刺激性功能。到目前为止，并没有充分研究显示服用鱼油是有效的。每个星期服用2至3份量的鱼油能确保身体有足够的 Ω -3脂肪酸。

3. 我是否该依据一些特别的饮食配方或者食用保健品，以便减少狼疮复发？到目前为止，并没有充分研究显示依据一些特别的饮食配方或者食用保健品能减少狼疮复发。最好是保持饮食均衡，多吃蔬菜水果，全麦，适量的低脂牛奶和奶类产品，瘦肉，肉类和鱼类。



Risk of Heart Attack and Stroke in Lupus

By Dr Aisha Lateef

Consultant

Department of Medicine, Rheumatology
National University Hospital, Singapore

What is Lupus and how does it affect patients?

Lupus is an autoimmune disease in which the patient's own immunity attacks the patient's body. Any organ can be affected and ranges from mild to very severe forms with kidney and brain involvement. Survival in lupus has improved significantly over the past few decades. In 1950s 50% of patients die within 5 years of diagnosis but now a near normal life span is expected. New problems have emerged with longer duration of disease. Now major issues leading to higher risk of death and disability are infections, heart attacks and strokes.

What is a heart attack?

Heart attack occurs when blood supply to a portion of heart muscle gets interrupted. As we grow older, the arteries get stiff and cholesterol gets deposited along the walls. Over time, clots form and bits of cholesterol break off from the arterial wall lining and get in the way of blood flow. The muscle in that area dies, leading to chest pain and loss of function in that part of the heart. Patients will then experience the typical symptoms of chest pain, shortness of breath and increased sweating. Some patients may feel the pain in the upper arm and jaw. Nausea, vomiting or sudden dizziness can also occur.

What is a stroke?

Stroke happens when blood supply to a certain part of the brain is suddenly interrupted. Symptoms are variable, depending on the area and extent of brain that is affected. Most drastic is the inability to move one side of the body but it can range from silent damage to severe disability.

Is the risk of heart attack and stroke increased in Lupus?

Yes, the risk of heart attack and stroke is increased in Lupus. All patients, even young women, have 5-10% higher risk than their healthy counterparts. This is due to many reasons including inflammation, sticky blood and more risk factors in patients with Lupus.

What are the factors that increase the risk further?

The general risk factors include high blood pressure, elevated cholesterol levels, diabetes, obesity, smoking, and inactive, sedentary lifestyle. Lupus-specific risk factors include active disease, longer disease duration and long-term corticosteroid use.

Is there anything that can reduce the risk?

Yes, the risk can be reduced by controlling the risk factors and Lupus activity. You can help to reduce the risk by having an active lifestyle. Exercise regularly but avoid sudden bouts of heavy exercise. Develop a routine that suits your condition. Watch your diet, maintain your weight, avoid smoking and take your medicines regularly. Good control of blood pressure, cholesterol and diabetes will significantly lower the risk of heart attack and diabetes in all patients, including patients with Lupus.

Disease Control is very important as uncontrolled disease with more inflammation translates into higher risk of heart attack and stroke. You should consult your doctor regularly and take your medicines as prescribed. Corticosteroids and other medicines (such as Imuran, Cellcept, Cyclophosphamide) can sometimes cause side effects but they are necessary to control the disease, which in turn results in lowering the risk of heart attack and stroke. If you encounter problems, discuss with your doctor and explore options. Do remember, close cooperation between patient and doctor is required to achieve a good disease control.

心脏病和中风的风险

红斑狼疮是什么？它如何影响病患者？

红斑狼疮是一种自身免疫性疾病。体内的任何器官都有可能受影响，影响范围可从轻微到非常严重并涉及肾脏及脑部活动。病患的存活率在这几十年已显著提升。在50年代时期，50%的红斑狼疮病患在被诊断后的首五年就过世，但如今，病患的寿命大多与常人一般。随着病龄的增加，其他问题，例如感染、心脏病和中风都有可能出现。这些并发症都会造成更高死亡和残疾的风险。

心脏病是什么？

当血液不能循环时，心脏病可能发生。随着年龄的增长，我们的身体也会老化。体内的动脉僵硬时，胆固醇就聚集在动脉的四周。血块和胆固醇便渐渐地堵住动脉，使血液不能循环。这会造成周围的心肌坏死，并导致胸口疼痛和心脏功能退化。病人可能会出现以下症状：胸口疼痛，呼吸困难、大量出汗、手臂和下巴疼痛，反胃、呕吐和头晕。

中风是什么？

当脑部所需要的血液供应突然停顿，就可能中中风。病人的症状会随着脑部问题有多严重而因人而异。中风可以对身体造成无声的伤害，也可在最严重的情况下影响身体一侧。

红斑狼疮病人是否具有更高心脏病和中风的风险？

是的，所有病患，包括年轻女病患者，会比常人高出5-10%的病发几率。炎症，血液凝固等因素都可能造成更高风险。

什么因素会造成更高的风险？

一般因素包括高血压、高胆固醇、糖尿病、肥胖、抽烟和缺乏运动。与红斑狼疮有关因素包括活跃性疾病、长期患病时间和长期服用皮质类固醇 (corticosteroids)。

有什么措施可以减轻风险吗？

有，我们能通过控制以上所举例的风险因素及红斑狼疮病情或定时运动来减轻风险。但是，如果长时间没有运动的话，就得在病发初期时避免剧烈的运动。

此外，您可以制定一个适合您的病情的例程并注意自己的饮食和体重，要避免抽烟，定时吃药，控制血压，高胆固醇和糖尿病等。这些举动，特别是对红斑狼疮病则而言，能减轻心脏病和中风的风险。

控制病情是很重要的。因为不受控制的病可引发更多发炎病状，也会提高脏病和中风的风险。因此，病患该定时复诊并服用药物。虽然皮质类固醇 (corticosteroids) 和其他药物 (Imuran, Cellcept, Cyclophosphamide) 有时候会有副作用，但它们能有效控制病情，从而减轻风险。如果您有任何疑问，请与您的医生商量，找出一个可行方法。请铭记：病人得与医生共同努力，控制病情。

Tribute to Nancy Chin

By Irene Lim

Nancy Chin, the ex-President, has left me 'big shoes' to fill in. I first heard of Nancy when I contacted the LAS office in 2001 after I was diagnosed with Lupus. Then, I was highly anxious about my condition and undoubtedly needed support and encouragement. I was given Nancy's contact number (her personal mobile number, no less) by the then admin staff. The first phone call to her gave me the much needed boost and confidence that all can be better and well in spite of my illness. She was assuring, comforting, knowledgeable and she managed to address most of my anxieties. A couple more phone calls to her in the fretful early days of my illness and I was consoled in the belief that I can be well enough to lead a normal life. What a wonderful job she did in helping me overcome my unease and fear. Nancy herself was diagnosed with Lupus in 1982, after suffering 2 years of the symptoms. Her journey with Lupus has been a very long and difficult one. At one stage, she went through one of the darkest periods of her life when she was bedridden for about two and a half months. Unable to move or function on her own, she often described those days as 'humiliating and degrading' as she was not even able to perform the most basic functions like using the toilet, combing her hair etc. Her early days with Lupus was also filled with long periods of hospitalisation. It was during those dreadful long stays that she realised how lonely and depressing it can be for the patients especially when the visitors fizzle out over time. It strengthened her resolve to help fellow Lupus patients through sharing and comforting during the ward visits, which she steadfastly adhered to through the years.

In 1986, Nancy, together with fellow patients and a group of doctors from Tan Tock Seng Hospital Rheumatology Department, formed a support group called SLE Aid Group to help patients.

In 1991, Lupus Association (Singapore) was formed, and now has 430 members, supported by doctors from the National University Hospital, Singapore General Hospital and Tan Tock Seng Hospital in the Council. Being one of the founding members, Nancy has been a volunteer for 25 years and was the President of LAS for 8 years from 2002. She extended help especially to needy patients, at times, persuading her friends to make personal donations directly to support poor patients. She even extended help to patients' family members when she learned that they were sick or financially strapped.

In her tireless strive to better equip herself to support patients, she took up a 2-year part-time course in Clinical Pastoral Care at the Mt. Alvernia Hospital. Nancy is

definitely a 'living testimonial' for patients and volunteers alike. She is a role-model to all of us at the LAS and even though she has stepped down as President, we look forward to continue working with her and tapping her vast experience and knowledge in volunteerism and patient care and support.

Thank you, Nancy!

向Ms Nancy Chin致敬:



前任狼疮协会主席, Ms Nancy Chin, 为协会做出了许多贡献。在2001年, 我被诊断患上狼疮后就联络狼疮协会。在那里, 我初次认识Nancy。当时, 我很着急, 实在需要他人的鼓励支持。有人便给我Nancy的个人联络号码。第一通电话就给予我极大的鼓励。她安抚我, 并解除许多困扰。在患病初期, 我连续打了好几通电话, Nancy都鼓励我, 让我有信心过一般人的生活。Nancy真的非常热心。Nancy本身在1982年被诊断患有狼疮, 当时已有两年的病情。她与病魔抗战的过程很是艰辛。有一段时期, 她足足有两个半月卧病在床, 度过人生最黑暗的日子。当时, Nancy 无法自个儿活动, 甚至不能独自如厕, 梳头等。因此, 她常将那些日子形容为极具屈辱性的。早期时, Nancy也常常住院。就是那时候, 她会尽病人孤独沮丧的滋味, 特别是无人探望的日子。这使她具有多年来持续鼓励病人的决心。

在1986年, Nancy、大家及风湿部门的一群医生一同组织 "SLE Aid Group" 关怀小组, 协助病人。在1991年, 狼疮协会成立了。如今, 狼疮协会有430会员, 以及国立大学医院、新加坡中央医院和陈笃生医院的医生的援助。身为狼疮协会的创办人之一, Nancy在过去的25年来当义工, 乐此不疲, 并自2002年当任8年的主席。她常常帮助有经济负担的病人, 有时候, 也劝说朋友捐款。当Nancy听闻病人家属生病或者是有经济负担时, 她也会帮助他们。

此外, 为了能更有效地给予病人帮助, Nancy也在麦里兹医院上了两年的医疗课程。对所有义工和病人而言, Nancy真的是一名最佳的模范。她是我们学习的好榜样。虽然她已卸任, 但我们很期待在未来的日子里与她一同合作, 学习她在义务服务及病人援助各方的精神。

Nancy, 谢谢你!