

Learning to Live Well with Lupus

Part 1: Physical Measures

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Lupus is a lifelong, incurable disease and can involve making major lifestyle changes and adjustments. The challenge facing many of those living with lupus is that lupus interferes with and affects many aspects of daily life, such as physical functioning, the ability to work outside the home and earn an income, or the opportunity to socialize with friends and family. People living with lupus often need to adapt to complicated medical regimes to control symptoms and prevent flares. Making gradual and achievable lifestyle adjustments can assist in improving quality of life and provide a sense of well being.

Learning to live well with lupus implies multiple tasks and coping skills that can be adapted for each individual person. The signs and symptoms of lupus can be different for each individual, so your plan will be personalized to your particular situation. Learning methods to help yourself involve a two-pronged approach of learning physical measures and developing some preventative coping strategies. Some of these approaches may be applicable to your situation and others may not be practical. Start with something you think might be enjoyable and something you will be able to accomplish. This will give you confidence to try other methods and will make it easier to add to your own personal plan.

Learning Physical Measures

1. Avoid the sun

Where sun exposure is unavoidable, apply a sunscreen lotion that has a sun protection factor (SPF) of 45 to 60. The SPF prevents ultraviolet A and B rays from causing rashes and/or activating lupus disease activity. Plan outdoor activities to avoid the most intense times of sun exposure between the hours of 10:00 AM and 3:00 PM. Wear loose, protective clothing over exposed skin. A large brimmed hat will protect your face from sun exposure. Remember that the intensity of ultraviolet rays increases at higher altitudes, so if you are hiking or skiing in the mountains, your risk of sun exposure is higher.

2. Eat well

Optimize healthy food choices. This sounds so simple, but is often very difficult when we have developed a pattern of eating foods that, over the years, could be aggravating or causing additional health problems that may or may not be related to lupus. Start by considering and following these few simple “wellness tips”:

- Balance calories consumed with calories burned; the amount of physical activity required to burn off high calorie, fast food meals is much higher than the activities required for lower calorie, generally healthier foods.
- Select natural foods, they are healthier and more nutritious; fast food or pre-made foods tend to have a higher calorie and fat content.

- Choose foods which contain plenty of complex carbohydrates and fiber. This includes grains, nuts, vegetables and fruits in a rainbow of colors. Ensuring a diet of 8-10 colors will introduce a number of health enhancing and cancer fighting phytonutrients to your daily diet.
- Keep yourself well hydrated with water; at least two litres of water every day especially if you are taking daily medication.
- Develop awareness of the type of fat you are consuming, lower your intake of animal fats (saturated fats) which tend to contribute to heart disease and cancer; fish oils tend to be beneficial for those with lupus and there have been research studies to suggest that a regular diet that includes fresh cold water fish (e.g. salmon) or fish oil supplements (alpha-3 omega fatty acids) can have a modest anti-inflammatory effect.
- Consume higher amounts of unsaturated fats, as found in fish, nuts, seeds, and some vegetable oils.
- Consider taking supplements and discuss with your physician or a nutritionist the potential benefits of vitamin C, vitamin E, B complex, and a good multi-vitamin which also contains trace minerals.
- Avoid extreme diets; stay away from dueling diet doctors, their tapes, books, and special foods.
- Eat breakfast, every day for an energetic start to wellness.

3. Get active

The physical functioning of your body has an enormous influence on your mind and your ability to deal with the day to day challenges of living with lupus. Pain, fatigue, and a range of symptoms and problems can stand in the way of engaging in physical activity. With prolonged inactivity, we become less energetic, lose muscle tone, balance, and place ourselves at higher risk for developing further health problems. The key to starting any exercise or activity program, particularly if you have been inactive for a long period of time, is to start slow, set short term goals you are sure to reach, and begin by doing something you enjoy. Beginning an activity program with a friend or “buddy” may give you the added boost of social support that enhances your exercise experience. Gradually increase your goals to aim at exercising for 30 minutes on 3-5 days each week. Try to weave your activity plan into your daily routine so it becomes a natural part of your day rather than an “extra” that can quickly be dropped if other pressures develop. The benefits of physical exercise are numerous and can include:

- Stronger bones, increased strength
- Improved sleep, decreased blood pressure
- Better sex, delayed aging
- Weight loss or maintenance
- Improved flexibility, enhanced energy
- Stress resiliency and clearer thinking

Daily movement is vital to wellness. Learning to be active is one piece of living well with lupus. The human animal has a constant interchange between mind and body. We actually think better when we are physically active. To reach our best potential as humans we have to find our play and preserve our best potential for health.

4. Consult an occupational therapist (OT) or physiotherapist (PT)

These health professionals are excellent resources if you require assistance with daily movement and activities. A PT can provide valuable assistance to get you started on a therapeutic exercise program. Exercise was once thought to increase pain and inflammation of the joints. Physiotherapists now know from research that dynamic exercise can help reduce overall pain with no negative effects on disease activity or inflammation. Exercise can take many forms including flexibility, strengthening and aerobic conditioning. A physiotherapist can assist you in overcoming barriers or problems you might encounter as you learn to include activity in your day to day routine. They can also assist you with learning to use techniques such as the correct application of cold, heat, or massage to manage pain, stiffness or weakness. Occupational therapists are the experts in learning ways to use your body to ensure you capture the benefits of activity, but don't harm yourself. They can help you learn various strategies in reducing the stress from normal activities while you work or play. OT's can provide advice on splints or braces if you have problems with painful or inflamed joints. They can also help you learn to use adaptive equipment that allows you to maintain independence in such areas as personal hygiene, maintaining a household, or continuing to work outside your home. OT's and PT's are also trained to give advice to improve posture and gait if you find these are problems. They are also an excellent resource for helping you learn to find the balance between rest and activities. Talk to your doctor or other health care professionals about where you could seek the assistance of OT's or PT's. They work in the public health care system and in private practice settings.

5. Stop smoking

This is the single most important action you can take to improve your health immediately. Smoking can aggravate many problems in lupus, such as Raynaud's, and is well known to increase the risk of cardiovascular disease. Due to the inflammatory nature of the disease of lupus, people with lupus are already at increased risk for cardiovascular disease and smoking simply multiplies that risk. It is also very difficult to quit smoking because of the powerful effect of nicotine in the body. Smoking cessation involves the physical act of stopping and also dealing with the psychological reasons why smoking was or remains important for you. Talk to your doctor about methods to assist with smoking cessation. You will require support and guidance to cut down and remain a non-smoker. A nurse, psychologist or social worker with skills in this area can be of assistance. There are also many community resources, as well as services and programs in the public health system.

6. Manage your pain and fatigue

Some of the physical causes of symptoms in lupus can be related to an increase in inflammation and disease activity in lupus. Pain management in lupus is an important physical measure because if left untreated can lead to increased fatigue, stress and can contribute to depression. These distressing problems can aggravate lupus disease activity and get you trapped on a cycle of endless pain, stress, fatigue, depression, and disturbed sleep. This can lead to a very poor quality of life and a lowered sense of well being. Any new pain symptoms should be discussed with your doctor to sort out – is this lupus or something else? – and what is the treatment? Active inflammatory lupus requires treatment that sometimes involves medication. Despite active treatment, pain sometimes continues to be a problem. Although this may reflect the ongoing presence of inflammation, sometimes it means that pain signals to the brain have continued despite treatment of the underlying inflammation. Pain means different things to

different people and the perception of pain varies between individuals. Pain perception is influenced by a variety of factors including environmental conditions, psychological issues, and physical problems. Pain is a serious symptom and needs to be appropriately managed. You can learn measures to self-manage pain in addition to the measures prescribed by your doctor to control lupus disease activity. Some successful self-management techniques are:

- Keeping active; adhering to your daily exercise plan
- Balancing activity with rest; pacing activities
- Application of cold (gel packs, bag of frozen vegetables) to affected areas for 15-20 minutes; do not use cold if you have Raynaud's syndrome
- Application of heat (hot water bottle, seed or husk filled cloth bag that can be microwaved) for 20-30 minutes
- Transcutaneous electrical nerve stimulation (TENS); applied to certain part of the body to block pain signals; requires instruction from physiotherapist
- Massage or topical creams
- Adopting joint protection techniques (adaptive equipment or splints) to reduce strain and stress on inflamed joints
- Using good body mechanics and posture to reduce strain leading to muscle weakness and fatigue
- Learning mind-body pain management techniques such as positive thinking, distraction, visualization, relaxation or meditation
- Use of appropriate analgesic medications, as discussed with your doctor

A final note

Making changes is not an easy process and doesn't happen without some bumps along the road. It is a gradual process that involves making smaller changes that can lead to achievement of larger lifetime goals. These ideas may help you in your journey of adaptation and learning to live well with lupus.

The next issue of The Lupus Lighthouse will conclude this article with Part Two: Developing Preventative Coping Strategies.

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