

Autoimmune Resource & Research

Centre
ARRC



Level 2, Pathology Building, John Hunter Hospital
Ph: 4921 4095

LIVING WELL WITH LUPUS

By Stephen Balch, MD, Medical Director, Jacquelyn McClure Lupus Treatment Centre, Inc. (This article is reproduced with thanks to Lupus Foundation of America Inc. "Facts about Lupus" No 2).

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INTRODUCTION

It may often seem to a person with lupus that "Living Well with Lupus" is an impossible task. The term "wellness" is often misused. In fact, a completely well-functioning person is probably as elusive as a car that requires no repairs. All individuals are exposed to a variety of physiologic and psychological insults in our daily struggles. In many cases, the key to our functional status lies with our success in dealing with these inevitable roadblocks. So, given that obstacles face us all, let's push ahead and see how it is, in fact, a realistic possibility to live well with lupus.

W = What You Eat

Person suffering from any disease are often told that one or another diet can help control or cure their illness. This is especially true with a disease such as lupus, many unproven and unsubstantiated ideas are proposed as to how to help or cure the disease. Diets are certainly a common method offered as a potential cure. To date, no known diet has been devised which has been proven to cure, prevent, or improve lupus. However, this does not mean that diet and nutrition are not important factors in your living well with lupus. The following suggestions concerning your diet may prove helpful.

- **Caffeine** - Keep the amount of caffeine intake to a minimum. Caffeine can increase your heart rate, cause some tightening of blood vessels, and appear to make you more susceptible to gastrointestinal difficulties. This is especially important to the person with lupus who has frequent stomach distress as a result of taking medications.
- **Fat and Cholesterol** - Follow a low-fat and low-cholesterol diet. It has been shown that a low-cholesterol and low-fat diet can help to keep your body less susceptible to certain complicating illnesses, such as heart disease. In addition, many patients taking Prednisone may be susceptible to increased cholesterol levels. This should be checked with your physician for monitoring and recommendations.
- **High-Fibre Diet** - A high-fibre diet, in some studies, has been shown to help with gastrointestinal problems. For example, frequently people with lupus will have difficulty

with what is called a "spastic colon" or "irritable colon". This can result in "bloating" of the stomach or excessive constipation or diarrhoea. A high-fibre diet can help to prevent some of these problems or help when they are, in fact, a problem.

- **Protein in the Diet** - In some studies, especially with patients who suffer from renal disease, the amount of protein can be an important factor in the diet. This, too, should be discussed with your physician.
- **Salt Intake** - Salt restriction can help in the control of lupus. For example, in lupus patients with kidney disease, restriction may be important, particularly when there is also elevated blood pressure or excessive swelling. In addition, people with lupus who have too much fluid in their body due to heart problems may be aided by reducing salt intake.
- **Vitamins** - A healthy body requires dozens of nutrients. Many people feel that if they take supplements, their health balance will be improved. In fact, supplements are much more costly than foods which supply the proper nutrients. In most cases, it is better to spend money on good food rather than vitamin supplements. Some vitamin supplements, such as vitamins A and D, can accumulate in the body and may cause serious health problems if taken in larger than needed quantities.
- **Minerals** - Minerals can have an effect on your health. For example, there is evidence that diets too low in calcium may contribute to osteoporosis. Some people with lupus may need iron; this should be discussed with your physician. Be sure to remember, however, that minerals are in a proper balance in your body. If taken in larger than needed quantities, they can be harmful.

E = Exercise

People with lupus face a difficult problem about the question of exercise. Recommendations for exercise for other general population are not the same as for people with lupus. For example, many lupus patients are deconditioned because of chronic illness. Just as muscles atrophy or lose firmness after being in a cast too long, our body can lose its shape if it is not appropriately used. In addition, people with lupus may note that they feel worse after they have exercised. In fact, recent studies have shown that appropriate exercise programs, under the supervision of a physician, can improve the conditioning of people with lupus and, as a result, positively affect the course of the illness. Such exercises as swimming and walking can improve one's health status.

A good rule of thumb is not to do too much, but not to do too little. As with many other aspects of living with lupus, moderation is the key to success. Exercise may be incorporated as a part of a physical therapy program and an individualised approach should be discussed with your physician and/or physical therapist.

L = Looking Good

Probably all people with lupus are tired of hearing the question: "You look so good how can you be ill". Sometimes you wonder if it would be better to try to look as ill as you sometimes feel. This mind set is, of course, unacceptable. Attention to simple details can be tremendously important to one's overall feeling of self-worth and confidence, as well as successfully coping with lupus.

Cosmetics can be appropriately applied to cover up some of the side-effects of medications, such as facial puffiness from prednisone, as well as many of the skin lesions. A simple cosmetics session can teach you what you need to know about the corrective uses of cosmetics, including attention to hairstyling. The application of sunscreens, required by many people with lupus, is compatible with the use of cosmetics. Attention to how you dress can not only make you look better, but also feel better. Finally, a large part of looking good

involves feeling good about oneself. Beauty is, as we hopefully are all taught, not skin deep; it is not difficult to see the inner beauty and strength in people. This view of the world - looking beneath the surface - affects both our image of ourselves as well as our impressions of others.

L = Living Well

One of the most difficult adjustments people with lupus encounter is that of attitude. It is not unusual for people with lupus to feel that they can no longer enjoy living because of their chronic condition. The result is depression and living a less than full life. This vicious cycle can be avoided. There are several ways:

- **Family and Friends** - An old, but generally true cliché is that family and friends are the most important assets we have. Accordingly, this item ranks as number one in a list of suggestions. Sometimes, people with lupus mistakenly feel that they are a burden rather than a valuable asset to their family and friends. It is important to remember that in order to have good friends, it is necessary to be a good friend. Friends, in turn, are an irreplaceable source of understanding and concern. Keep them informed about what is going on with your disease so that they can help.
- **Medications** - Often, there are little tricks that will maximise the benefits of medications and minimise their adverse effects. For example, taking certain medications with meals can minimise the gastrointestinal distress the medication might cause. Ways in which to reduce possible side effects of medication should be discussed with your physician.
- **Outside Interests** - Outside activities, such as volunteer work for your Support Group or any other organisation or having a hobby can be an invaluable way of building and maintaining a positive outlook. Such activities provide a way to meet people, be involved, and feel satisfaction. Without outside interests, we are likely to become uninteresting and unexciting - to ourselves as well as others!
- **Good Medical Care** - A physician experienced in treating lupus is essential for your proper care. Perhaps the most important aspects of good medical care is ongoing education about your disease and proper management. In addition, a good team relationship between you and your physician is imperative!
- **Sex** - Nothing about lupus precludes having a good sexual relationship. Sex can be an important component of a quality life. Some partners may fear that sexual activity will be harmful to the person with lupus. The reality is, this is seldom the case. Frank, open discussions concerning sex with one's partner can be a step toward a happier relationship.
- **Helping Others** - The person with lupus often feels so fatigued that it is a struggle to simply deal with the everyday necessities of living. But getting outside of ourselves is often the first step to feeling better. Many people with lupus have greatly improved the quality of their lives by providing assistance to others. This may take the form of participating in lupus support groups or answering "hot line" or emergency calls.
- **Counselling** - Seeking and receiving counselling does not imply that one is "crazy". To the contrary, getting help is a mature sign of recognising your difficulties and coping with them. Most everyone these days experiences occasional "stress overload" periods and could benefit from some form of counselling. Counselling should be strongly considered when you are feeling under stress or are experiencing depression.
- **Education** - Education about one's disease is invaluable. People with lupus, as well as health professionals, should consistently keep up-to-date with the latest information about the disease.

As you may have noted, the first letters in each section of this article spell out the word "WELL". The suggestions offered can contribute to living well with lupus. This is an

obtainable goal. All people with lupus have the capacity to truly live full and productive lives. Don't make yourself the major stumbling block to accomplishing this goal!

Reviewed by: Sister Rachel Robinson, August 1994
Reviewed by: Sue Barwick - Registered Nurse - September 2002

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