

# Living Well With Lupus

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## **What Is Wellness?**

How can a person with a chronic illness live well? For many people with lupus, living well means adopting a wellness philosophy. Wellness is an approach to living and the first step, in achieving wellness is understanding what it means to be “well”. A wellness lifestyle requires attention to the body, the mind and the spirit. It requires thoughtful planning and carefully adjusting your daily routines. Living well with lupus is a struggle at times, but is achievable and well worth the effort.

Wellness means making a decision to be the best you can be and then taking responsibility for doing what helps or hinders your life. This requires you to understand and accept that everything you do to your body, think with your mind and believe with your heart has an impact on your state of health. Health is affected by your state of wellness, but wellness is about more than health. People who are ill, disabled and even those in their final days of living can experience wellness. Wellness is choosing options and making commitments which enhance life. To live well with the challenges of lupus requires coping with the impact that a chronic illness has on the body, the mind and the spirit. These three areas are inseparable; improvement in one leads to improvement in the others.

Wellness doesn't just happen; it must be worked on every day. It must be carefully planned with a positive outlook and a realistic evaluation of your potential. Living well with lupus requires a balanced plan. Maintaining balance includes: identifying what you want to do in each area, setting goals and making a contract with yourself. In essence, you make a commitment to start living and enjoying a wellness lifestyle. This commitment puts you in control instead of being controlled by an illness.

## **The Wellness Mind**

People with lupus are not responsible for developing the disease, but they are responsible for the way they react to it. Attitudes, feelings and thoughts have an impact on health. The wellness-oriented mind is one that chooses to see the world in a positive light. To live well with lupus, focus on your abilities rather than your disabilities. Whether you choose to view yourself as active and responsible for your life or as a victim of disease is a personal choice.

Planning includes thinking through your daily and weekly commitments and then looking for energy-saving short cuts. Visualize what needs to be done and decide if you are physically up to it. Be flexible; if you don't have the strength to do it today, it may wait. Or tackle the task piece-meal; do what you can now and save the rest for later. If you push yourself when you do not have the physical energy to complete a task, you may pay

for this with more fatigue. A positive attitude coupled with a well thought-out plan of action will increase the likelihood of success.

Your attitudes, thoughts and feelings are truly your own and you are free to change them as you develop a wellness mind set. If you find you are afraid, bored, confused, distressed or depressed in your life, there is nothing that says you have to keep those thoughts and feelings or be controlled by them. You can choose to change. You can make the decision to adopt a new attitude, and then take steps to make the change happen. Life is a choice and it is yours to make.

### **The Wellness Body**

To operate efficiently the human body requires fitness, nutrition, and stress management. Fitness is important because it can prevent unwanted problems such as obesity, muscle weakness, low energy or fatigue. It also can cause desirable effects such as increased stamina, vitality and confidence. The joint pain, fatigue and muscle weakness frequently found in people with lupus can lead to physical inactivity and reduced fitness. Rest is an important component in managing fatigue. It may be necessary to increase the length or number of rest periods in times of a lupus flare. As important as rest is, it is necessary to seek a balance between sufficient and excessive rest. Excessive rest is harmful to the joints, muscles, bones and overall fitness. A lack of fitness may be indicated by: unexpected weight gain, sore muscles after routine or increased use, or a loss of strength or endurance.

Studies show, fitness can be improved in people with chronic systemic diseases without undesirable side effects. Your doctor or a physical therapist can recommend an individualized home exercise program. The keys to achieving your ideal level of fitness are:

- to find an activity that interests you
- to make a commitment (and put it in writing) to your exercise plan
- to recognize ways you might try to talk yourself out of sticking to your plan
- to list the payoffs you expect from fitness
- to chart your progress. You can take pride in taking control and being as strong and fit as possible with lupus.

Nutrition provides the necessary fuel for the body to carry on its normal functions. Your body requires a balance of nutrients. Fad diets are to be avoided because they are nutritionally unsound. Eating well and wisely is essential to achieving fitness and living well. There are no specific dietary guidelines for people with lupus other than to observe a balanced diet that includes the appropriate amounts of food from each food group. Several studies on the effects of diet on disease have identified three dietary recommendations for general health:

- Eat a balanced diet
- Include a variety of foods from all food groups; eat foods that are: low in fat, high in fiber, and less refined
- Eat and exercise to maintain ideal body composition.

Corticosteroids often increase the appetite and unless you are careful, unwanted weight gain can occur. Realizing that overeating is inconsistent with a wellness lifestyle is a step toward controlling weight and practicing wellness.

If you want to lose weight, focus on two things: increasing your exercise and decreasing your fat intake. Exercise increases the amount of lean muscle mass and increases the body's capacity to burn up fat. How do you know if you are eating too much fat? Record everything you eat for one day. Consult a dietitian or nutrition book to determine your fat and caloric intake. Fat calories should make up no more than 30% of the total calories. Set realistic goals for how you will improve your diet. Be patient; changes in diet takes time (weeks) before results are seen. Be wary of reports that make outrageous claims for easy weight loss. Reports from genuine scientific research that use controlled studies and find the same results in more than one laboratory, are probably authentic. When it comes to wellness, there are no quick fixes. The most important actions you can take to maintain physical wellness include eating properly, exercising and maintaining your weight at a proper level.

Stress management can be achieved by using various self-help techniques. Lupus affects many aspects of living: family and intimate relationships, vocational status, finances, self-esteem, mood, morale and one's sense of personal control. Managing the stress that occurs in these areas can be a struggle and at times, it can be overwhelming. Scientific studies show that people who are actively involved and believe they have some control in life situations are more healthy than people who are passive and believe they are helpless victims.

Participation in a support group can provide social and emotional help. Support groups can also help individuals develop or improve their coping skills which alleviate some stresses of chronic illness. Support group participation bolsters self-esteem, morale and self-reliance. Working to improve patient-doctor communications is a way to help one gain a sense of control and reduce stress.

This can be accomplished by the following:

- prepare for doctor visits by making a list of questions and a brief outline of current problems
- keep a medical diary
- take medications with you
- ask how and why a medication needs to be taken
- if a medication causes a problem, notify your doctor
- make it a goal to understand your doctor's advice. You and your doctor are equally responsible for maintaining clear communication about your health and wellness.

### **The Wellness Spirit**

When a person is diagnosed with a chronic illness it can have a profound affect on their self-concept and what's important in life. It is an emotional experience and a period of grieving is commonly needed. People with lupus often go through periods of denial,

anger, fear, depression, bargaining and finally, acceptance as they come to terms with the diagnosis and perhaps reshaping your life takes time. Allow yourself to grieve for the loss of your life before lupus, so you can accept and redefine your life with lupus.

This process of redefining your purpose in life and who you are is seldom easy. Often it is made more difficult by a lack of information about lupus. Understanding what lupus is and what to expect can diminish the fear of the unknown. Developing a wellness-oriented spirit is a process that evolves over time. Just like developing a wellness body, planning is key to developing a wellness spirit.

The plan includes:

- adopting a positive attitude
- developing a passion for something outside of yourself; something around which you can focus your life.
- striving to be happy.

In the words of Abraham Lincoln, “Most folks are about as happy as they make up their minds to be.”

A richer way of life can be achieved by exploring who you are, why you are here and what you can do. Discovering who you are is a wonderful thing. As a sense of purpose in your life develops and takes form, the mind, the body and your general well-being will benefit.

### **Summary**

Wellness is a philosophy in which one takes responsibility for the positive development of the mind, the body and the spirit. It is your conscious choice to pursue behaviors that enhance and enrich life. Wellness requires that you develop and use a plan based on your realistic potential. A plan for wellness includes striving to improve each area: the mind - through emphasis on developing positive attitudes; the body - through attention to fitness, nutrition and stress management; and the spirit - through reflection on life.

How can you recognize people who are living well with their lupus? They are individuals who focus on their current talents and abilities. You will rarely hear them dwell on what they used to be able to do. Their life with lupus has new meaning. Making the best of the present and planning for the future is what is important to them. People who are living well with their lupus understand that options and alternatives are available.

They control their life instead of letting lupus control their life. They have successfully navigated through the grieving process, and will tell you it was not an easy trip. Through acceptance, they have reached an understanding that lupus is not their whole life, only a part of it. They take responsibility for their health and wellness and are able to reach outside of themselves to help others.

Adopting a wellness lifestyle can make the difference between enjoying life versus simply surviving life with lupus. The choice is yours.

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