

## Autoimmune Resource & Research



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### **SYSTEMIC LUPUS - SELF HELP AND HOPE**

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A diagnosis of Systemic Lupus often causes severe anxiety in the newly diagnosed. The notoriety of the disease springs from the talks of patients and their loved ones severely afflicted by the condition and is reinforced by the traditional medical literature of the subject which, until recently, was almost entirely based on the worst cases, complications and outcomes. Indeed, even today, the young medical graduate leaves his or her training with a variable experience of caring largely for patients with severe lupus as they only see cases of lupus in hospital during a flare up. In reality, however, most patients with systemic lupus have a mild disease. The vast majority can anticipate a nearly-complete and unrestrained lifestyle, achievement level and longevity. Even patients with serious disease often display a much milder course once the initial crisis is overcome and safe long-term therapy instituted.

It has been gratifying to observe the large number of patients who can manage their disease with a combination of self-help measures combined with a rather mild regimen of medications. Many find that long periods of rest enable them to hold their medications to a minimum. Of course, this is not always feasible for everyone with lupus, but short spells of self-prescribed rest should never be underrated. At the same time, gentle exercise and conditioning programmes are encouraged, as in the population at large. Sometimes, however, the presence of troublesome arthritis or muscle inflammation calls for deliberate avoidance of heavy exercise. Like any other normal individual, a healthy well balanced diet is crucial for fighting the disease. This means avoiding obesity and extreme (fad) diets in incorporating excessive or deficient foodstuffs, minerals or vitamins. Despite the large amount of literature and press addressing dietary regimens in disease prevention and management, no convincing scientific data has yet emerged on the role of diet in systemic lupus. Of course, an individual patient's awareness of adverse reaction to certain foodstuffs should not be ignored but it cannot be applied to others with similar expectations. Most patients are warned to avoid the sun, including more subtle forms of exposures such as burning through the windows of the car. For many people, strict sun avoidance is a worthwhile self-help measure and the availability of strong barrier creams has made the task quite attainable. Finally, sufferers of lupus often face a chronic disease, mild or severe, which must be lived with and dealt with for many years. A fortified emotional state helps. Self-help groups, psychotherapy (individual or group), frank discussion with family and friends and a comfortable and trusting communication with health care providers all serve to strengthen patients' resolve to take charge of his or her disease and not become a victim of it.

#### **MORE EFFECTIVE DRUGS**

A striking feature of the current treatment modalities employed for patients with more severe forms of the disease has emerged. This is in the form of a more effective and safer use of our older drugs. A wider role for the antimalarials; safer regimens for corticosteroids; clear guidelines and better directed use of immunosuppressive agents; they have all resulted in a marked decrease in the serious drug complication rate. Furthermore, a series of lupus crises intervention treatments (eg. pulse steroids; plasmapheresis etc.) have had a marked impact

on patients with severe lupus. Once through the crises, patients with initially severe systemic lupus can be expected to well, eventually.

Even patients with continuously severe disease have cause for hope. Quite apart from the better developed crises intervention techniques, all the miracles of modern medicine are available for patients with infections, heart or lung disease and renal insufficiency. Indeed, the advances in Internal Medicine and renal transplantation have had an enormously favourable impact on the quality of life in even the most severe cases of lupus. Moreover, newer and specific treatment measures are bound to evolve and appear on the medical scene. The explosive growth of modern immunology, virology and oncology will provide tremendously valuable "spin offs" for the treatment of autoimmune disease. If the outlook for patients with lupus has improved in the last two decades, just imagine the potential impact of novel immunomodulation and anti-inflammatory agents yet to be developed and applied with all the research going on (in SLE and related fields), it is not too speculative to even wonder about the eventual development of prophylactic measures in individuals seen as being at genetic risk of developing the disease.

I believe that there is increasing hope for all lupus patients and the physicians presently, in the near future and on the distant horizon. The human impact of SLE will be further diminished in our lifetime.

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