

Important Goals, Concepts and Attitudes for Lupus Patients, Families and Doctors

By: *Howard Steven Shapiro, MD*
Neuropsychiatric Medicine/Psychopharmacology Beverly Hills, CA

Once upon a time, I was asked on a college history exam to summarize the Bronze Age in one paragraph (2" on the exam sheet) after three months of having studied that age.

Similarly, here I will try concisely, cogently and clearly to summarize my convictions and insights about dealing with persons with lupus, after having studied and treated patients for more than 30 years. My emphasis is on those notions commonly neglected, avoided, unrecognized, and, all too frequently, dismissed as unimportant by their healthcare providers, loved ones and, sadly, the patients themselves.

Firstly, doctors should direct all their efforts toward increasing the patient's sense of self-control and independence, and promoting open, honest participation with the healthcare team. What follows are suggestions for doctors, patients, and their families.

Doctors should recognize that:

1. Medical treatment of the patient with lupus requires greater compassion, patience, tolerance, flexibility and creativity than are needed to treat many other patients. It requires more common sense and acceptance of various and even stranger parameters than do shorter-term conditions.
2. The quality of the patient's life is as important as their physical condition. The focus should always be on quality of life.
3. Rarely should the physician attempt to deny or dispute the truth of a patient's accurate perception of the physician's attitudes, feelings or behaviors.
4. Pain and immobility may be more stressful to the physician than to the patient, and patients tend to be highly sensitive to their physician's emotional responses.
5. Physicians should make the effort to know and understand the personality, lifestyle, ego-strength, and the resources (including family) of the patient before treatment begins.
6. Physicians must understand what their patients are trying to communicate, since words and terms often mean different things to different patients. Physicians must accept their patient's emotional problems, which sometimes translate into physical ills and complaints, and vice versa.
7. Physicians should encourage mental health intervention without fear or hesitation and not to view psychotherapy as a substitute for vocational or social rehabilitation.

Patients and their families should realize that:

1. Despite major disruptions in their lifestyle and existence, most lupus patients recover their mental, emotional, spiritual and often sexual sense of well-being. They then want to continue their lives and to live well...and they do.
2. Realistic limits are essential, but exceeding those limits is inevitable, and serves to define better and to teach the patient what they can and cannot do.
3. Each and every inevitable loss (or sense of loss) the patient experiences should be neutralized and compensated with the development of some form of replacement. Patients must resist surrendering to a sense of helplessness and hopelessness as these emotional states exacerbate their lupus and their quality of life.

Recommendations for patients, their families and doctors:

1. The physician and the patient must develop a mutual honesty, respect, understanding of one another, and openness of communication to cope with aspects of the condition that are unclear, unpredictable, and often intolerable (but important).
2. The cornerstone of any good relationship is honest and open communication. Patients have the responsibility to tell the physician what really troubles them, and the physician has the responsibility not only to listen but also to hear. The physician must inquire not only about their patients' physical condition but also, and perhaps more importantly, about their inner feelings, relationships, and life situation. Communication is always a two-way street.
3. Many chronically ill patients with severe neuropsychiatric pathology have been neglected, and especially rejected, by a therapeutic pessimism that has led to under treatment, therapeutic and familial abandonment, and deepening psychopathology and maladaptation.

It is my hope that this distillation of suggestions and insights will be digested, acted upon and proved of value to you, as they have for others. It was the "others", who were the best teachers a doctor could have...my patients.

Reprinted with permission from Lupus World, Volume 4, No1, Winter 2003.