

Be Empowered!

Taking charge of your healthcare goes a long way toward coping with lupus

By: Gerri Miller

Although having a chronic illness can sometimes make you feel helpless, there are things you can do to feel more in control. Your healthcare is your own responsibility, and you (with your doctor) are the one who should make the ultimate decisions about your care.

Becoming an empowered patient means becoming a responsible member of your healthcare team. It means being better informed and more confident.

Be an equal partner. “If you’re discussing anything with a healthcare professional, it’s a matter of negotiation, not being told what to do,” says patient advocate Amye L. Leong. Following the “doctor-knows-best” belief may not always serve you well. Becoming empowered means understanding that “you are equal and an adult in the partnership.”

Get educated. Take advantage of support groups and lupus self-management courses to stay informed about lupus treatments. Surf the Internet, “but make sure that the sites you visit are authoritative,” advises Stuart Weinstein, M.D., first vice president of the American Academy of Orthopaedic Surgeons, and Ponseti Chair of Orthopaedic Surgery at the University of Iowa. “Your doctor can direct you to reliable Web sites or books,” he says. “A good doctor will give you the information you need or direct you to where you can find it.”

Be assertive. Speak up for yourself. Be polite, but don’t be afraid to express your feelings about what your doctor says or a medication he or she prescribes. Leong suggests, “Say to your doctor, ‘I know you say I have to take this drug, but can you help me understand why? And, with more information about potential side effects, I can better decide yes or no’”

Initiate discussion. Talk to your doctors about treatment options and your concerns, suggests Weinstein. “Go to a doctor who takes time to answer your questions, and prepare for your visit by thinking about those questions in advance. If questions come up after your visit, don’t hesitate to call back.”

Maintain a doctor-patient relationship based on trust and mutual respect.

“The doctor has medical knowledge and clinical experience but not the experience of living with the disease,” says Leong. As the one with lupus, you have experience and expertise, too. “Your role is to share that experience with the doctor to get the best possible advice so the two of you can make the decision about your care.”

Enjoy the benefits. Empowered patients report greater satisfaction with their care. Patients who share in decisions about their care are more likely to follow treatment and are more likely to adapt to living with a chronic disease. “If you feel good about your treatment, that eases some of your anxiety. When you have a chronic disorder, a positive mental attitude goes a long way toward coping with the condition,” says Leong.

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