



Your health care team is made up of many different specialists; doctors, rheumatologist, cardiologist, respirologist, neurologist, endocrinologist, dietician, physiotherapist, occupational therapist, psychotherapist, pharmacist, naturopath, chiropractor, osteopath, acupuncturist, massage therapist and others in the health care field. Your specific symptoms will determine which types of specialists make up your health care team.

Living with lupus requires the development of a positive relationship with a health care team. This is often a challenge for many people because we may feel intimidated by professionals who use words we don't know or become nervous about asking for further information if we do not understand. This anxiety can stop us from sharing important things with our health care professional.

Our doctors and other health care providers are also responsible for communication with us despite a busy schedule. As patients, we deserve the right to information about our health. It is important to remember that the relationship developed with our doctors and other health care providers requires commitment and work, just like any other relationship.

However, there are two things that may help in developing that positive relationship with your health care professional.

The first point is understanding that members of your health care team are human as well. They too have stresses to deal with on a daily basis. They may experience frustration when they are not able to offer a cure to someone with a chronic and often disabling condition such as lupus.

The second thing in developing a positive relationship is making good use of the time you have together. When you feel pressured for time, messages are not always delivered with the same care that more time would permit. Misunderstandings can occur.

One way to help get the most from your provider's time is to prepare an agenda of what you expect from your visit.

Take the time to prepare

Write a list of concerns or questions. Try to be realistic with your list as your provider can only deal with so many concerns during a single visit. Writing your concerns down also allows you to remember and prioritize them. Be sure to mention your main concern at the start of the visit.

Be as clear as possible

Describe the symptoms with regard to when they started, how long they have lasted, what makes them better or worse, and any possible contributing factors.

Bring a written list of any current medications that you are taking and any test results you think may be relevant. Have a second copy of these to give to your provider.

Asking questions and getting the information you need is important in receiving good care and is a positive self management skill in dealing with lupus. Taking notes or having someone else attend your appointment can be helpful. If you are uneasy with your current relationship or the care you are receiving, asking for a second opinion is acceptable.

It is helpful to repeat back to your doctor what you have heard in the appointment to ensure you have clearly understood. Repeating helps to clarify any miscommunication and you can also ask your doctor to write down instructions or recommend further resources for you to follow up on at a later date. If you can't follow the orders recommended, let the doctor know and explain your reasons why. This way adjustments can be made that are more suitable to your situation.

You also have the right to give your doctor feedback about the way you are being treated and your level of satisfaction with that treatment. If you are pleased with the care you have received then provide positive feedback. Everyone appreciates positive feedback and being told how their efforts are helping. This includes support staff, nurses, receptionists, technicians, etc.

Reference: Living a Healthy Life with Chronic Conditions by Lorig, Sobel, Gonzales, Minor and our experiences.

Further reading:

Patient Self-help Guide: How to Talk to Your Doctor
by Jane Williams ISBN 978-0976645629

The Intelligent Patient's Guide to the Doctor-Patient Relationship: Learning How to Talk So Your Doctor Will Listen. Barbara M. Korsch MD and Caroline Harding. New York: Oxford University Press; 1997. ISBN 0-19-510264-9. 272 pages.

How to Talk to Your Doctor: Getting the Answers and Care You Need by Patricia Agnew ISBN 978-1884956548 and ASIN B01FGN7Y54

Here is a final thought by Cicero, "Nobody can give you wiser advice than yourself."