



Our message to People living with lupus

Dear Lupus fellow,

So, you too have been diagnosed with lupus...

We, a group of people living with lupus in Europe met in Brussels with LUPUS EUROPE to discuss our lupus and how we can help each other improve our quality of life, having a particular focus on treatment. Here are a few things we would like to tell you:

Go to a doctor who really knows lupus. Don't hesitate to visit the best doctor, even if that means you need to spend some time travelling: lupus is a complex disease – everyone's lupus is a bit different from that of others, so it requires experience of seeing many patients to provide the best treatment. Always ask for the right doctor! When you visit explain well your symptoms, your feelings, and your concerns. Be frank, don't be afraid of asking questions, don't be ashamed! Before you go to the clinic, make a list of questions for the doctor... then remember to ask them. Sometimes, it is easy to forget an important issue or maybe you are not in your best day to lead a conversation: use your notes to make sure you have asked everything you were planning to [and if you are afraid of asking something to that eminent professor... maybe the nurse can help you].

Be actively involved in your illness and treatment. It is not just the doctor telling you what to do, it is also you agreeing that with him. Ask what the purpose is of each prescribed medicine, be in control of your situation: that will help you follow what the doctor and you agreed as treatment.

Ask your doctor how you could be involved in research. Maybe that is only having an extra blood test or filling in questionnaires, or maybe benefitting from a new treatment. Lupus is rare and complex, and we need a lot of research, so every patient that engages in research is truly helping our whole community. Keep yourself updated about your disease. Stay informed, but make sure your information comes from reliable sources!

Take your treatment regularly. Don't interrupt your treatment: it is important for your life. Even if you don't feel sick, you still have lupus. Understand what each medication is for what purpose and how it works: It might help you be motivated to take it. Tell the doctor why it may be difficult for you to adhere to your prescriptions. Together, you might be able to find a solution. Inform the doctors about any other drug or supplement you take. We can take many pills, sometimes interacting with each other, so your doctor should know what you take and if necessary adjust your treatment plan.

Stay in touch with your local patient organisation. They will supply you with important contacts, information, and good advice. We can help each other by exchanging our experiences. Your own experience can help others, and others can help you. Listen to what other patients tell you, but don't take decisions only according to what they said because our lupus symptoms are different, so what might work for one is not always good for others. Don't give up! Thanks to our patient support groups, you are never alone... and you are not the only one with lupus. We can all fight together against lupus!

Please do not forget: lupus is not the only thing in your life. When you get diagnosed, you have the impression everything else disappears and lupus becomes your entire life. Don't let that happen. Don't hesitate to speak about your illness, but also make sure to do other things, to follow your dreams and fulfil your ambitions. While lupus brings limitations, there are so many things that remain possible. Don't worry too much, but try to always be positive, keep moving, keep your life as much as possible like that of any other person.

Before we close our letter, we would like to say again a very important thing, one that can save your life, and will definitely improve your quality of life: Lupus can be like the mafia, even if you can't see it, it is always there. So take your medication because medication only works if you take it!

See you soon in one of our patient's groups!

LUPUS EUROPE Patient Panel on Treatment,
Jane, Jeanette, Claudine, Ana, Sander, Christine, Angela, Daniela, Davide and Bernadette

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