LIVING WITH LUPUS

JACKIE LEARNS HOW TO LIVE WITH LUPUS

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Jackie lives with lupus

The effects of the disease are always in the back of her mind.

Sometimes I feel like a walking medicine cabinet.

Just look at me: the medications have made me gain so much weight, but how can I commit to exercising when I am always so tired?

I want to go to the zoo... Can I have a puppy? I want to ride a giraffe...

Maybe tomorrow honey, let’s see how I’m feeling...

As for today, I’ll drop you off at day care, then when I get off of work I’ll...

...but I’m so tired, and my joints ache... I wish I could just have one normal day...
Jackie visits Dr. Hall

Hello, Doctor,
Thank you for seeing me.

Good morning, Jackie. I am sorry to hear that you haven't been feeling well. Let's see if we can figure out why.

Although it is hard, Jackie decides to be honest with her doctor.

I noticed that we don't have your symptoms under control, your blood pressure is high and your red cell count is slightly low. How have you been doing with your medications?

Well... I stopped taking the medicine for my skin rash and am only taking half of my daily steroid dosage because it feels like lupus is taking over my life...

Those pills are a constant reminder and sometimes I want to forget I have lupus.
Why me?  

How am I supposed to handle it?

It is just too much!  

I feel really alone in this.

The amount of medication, the cost, plus all of the side effects make life so hard.

Jackie, I know it isn’t easy to accept you have a chronic illness, but you must take your medication regularly for it to work effectively. You are not alone in how you feel. Others with lupus have similar experiences.

Not knowing how I’m going to feel the next day is frustrating. I also have to balance my career and my family. I just want to feel normal, Dr. Hall.

Your feelings are perfectly normal. Our nurse, Selena, can provide you with information on local support groups, if you are interested.
Jackie asks nurse Selena for information on support groups.

Many of our patients have found comfort in lupus support groups, Jackie. Speaking to others who live with lupus may help you feel more connected and less overwhelmed.

Your friends and family can also provide support. They can keep your spirits up and help you cope with the challenges of lupus.

Lastly, don’t forget that exercise and eating well have a big impact on how you feel. Try a walk when you feel stressed.

Thanks, Selena. I could really use someone to talk to. I’ll give it a try.
So she decides to follow Selena’s advice.

Later that night, Jackie feels overwhelmed.

What’s wrong, Honey?

...Hmmm?

This local support group meets in the evenings. That would work with my schedule. Better yet, here is an online support group!
Jackie signs on to an online support group and is surprised to find that many of the women feel the same way she does about living with lupus. They also have helpful suggestions!

**Lizzie:** Walking 20-30 minutes a day really boosts my mood. It is nice to get some fresh air and exercise. My doctor says exercise will help me control my weight and blood pressure.

**June2000:** I never knew that!

**JennySays:** ...and I said, girlfriend, if I didn’t have this drug, I wouldn’t be alive!

**Susan_38:** I knew that!

**CathJP:** I have finally accepted that I have lupus and now I feel more in control.

**Bethany007:** I told my doctor my side effects and she suggested that I try a once-a-day medication.

**Jackie_M:** Hi, I’m new here :)

**JennySays:** Welcome!

**CathJP:** Hey there!
Following Selena’s advice about the benefits of exercise, Jackie asks her sister to go on a walk.

Anytime, Jackie. I am always here to listen. I didn’t realize how hard this was for you. Please tell me how I can help.

Thank you for walking with me, Anna. I have been feeling overwhelmed and it’s nice to talk about it with you.
Feeling less alone and overwhelmed, Jackie is able to overcome her urge to ignore her lupus.

She starts walking everyday at lunchtime, takes time to relax each evening, and takes her medication as prescribed.
Back at Dr. Hall’s office...

Jackie, your symptoms are back under control, and you seem much happier.

I am, Dr. Hall. I no longer ignore my medicine, and Selena, I found comfort and support in talking with others facing the same struggles I’m facing. I am taking time to connect with family. We are even exercising together!

That is great! Remember you have lupus, but lupus does not have you!
Advice from a lupus patient

1. Don’t be afraid to ask questions. Taking control of your health means taking control of your life.

2. Ask your pharmacist and doctor about the best time to take your medicines. That will help with managing the side effects.

3. Don’t try to hold in all your emotions. Lupus can be overwhelming, so express yourself however you need to. You are not alone in how you feel.

4. Be kind to yourself by eating healthfully, exercising when you have the energy, and taking time to do things you enjoy.

5. Do something that makes you happy when you feel the side effects of the medication or symptoms of lupus. It will take your mind off what is going on in your body. Talking with your family, a friend, or a support group during those moments will help, too.

6. You may feel like you have control over your lupus for many weeks or months and then experience a setback. Do not let that get you down. Refocus and continue taking it one day at a time. Don’t give up!
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