

HOW TO EXPLAIN LUPUS TO OTHERS

Developing Your “About Lupus” Speech

Instructions: Knowing how to explain your lupus to others is an important skill to have in your toolbox. Mix and match answers to commonly asked questions about lupus and add your own responses to create your 30-second “About Lupus” speech. Sample speeches are provided at the end.

Q: WHAT IS LUPUS?

EXAMPLES

- Lupus is an autoimmune disease. That means my immune system is overactive and is causing inflammation and damage throughout my body.
- For me, lupus has affected: [list your organ systems affected].
- Lupus is also a disease of flares, when symptoms become active. Sometimes I know when a flare is coming, but sometimes it catches me by surprise.
- When I’m having a flare, it helps me to get extra rest, so sometimes I must change or cancel plans, or miss work.

ADD YOUR RESPONSE HERE

Q. IS LUPUS A KIND OF ARTHRITIS? OR IS IT LIKE HIV/AIDS OR LIKE CANCER?

EXAMPLES

- Lupus is an autoimmune disease. That means my immune system is overactive and is causing inflammation and damage throughout my body.
- Lupus is not a form of arthritis, but the joint pain and swelling of arthritis are also common symptoms of lupus.
- Lupus is not like or related to HIV/AIDS. In these illnesses, the immune system isn’t working correctly. The difference is that, with HIV/AIDS, the immune system is under-active; and in lupus, the immune system is overactive.

ADD YOUR RESPONSE HERE

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- Lupus is not like or related to cancer. In lupus, your immune system attacks healthy tissue (tissue is what our organs are made of). In cancer, some of the body’s cells begin to divide without stopping and spread into surrounding tissues.

Q: IS THERE A CURE?

EXAMPLES

- No, lupus is a chronic illness, which means it’s long-term.
- Right now, there’s no cure for lupus, but I hope that there will be one in my lifetime!
- No, not yet. That’s why I must take good care of myself and learn how to manage it.

ADD YOUR RESPONSE HERE

Q: WHO GETS LUPUS?

EXAMPLES

- People of all ages, genders, and racial and ethnic groups can develop lupus.
- In the United States, certain people are at higher risk for developing lupus than others, including:
 - Women ages 15 to 44
 - Certain racial and ethnic groups—including people who are African American, Asian American, Hispanic/Latino, Native American, or Pacific Islander
 - People who have a family member with lupus or another autoimmune disease

ADD YOUR RESPONSE HERE

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Q: HOW/WHEN WERE YOU DIAGNOSED?

EXAMPLES

- I was diagnosed [give the date], but now that I know more about lupus, I think I've had symptoms since [fill in details].
- Diagnosing lupus can be hard because the symptoms are seen in many other illnesses. For example, I had [fill in your first known lupus symptom(s)], which could also have meant I had [different illness with similar symptom(s)].
- It took [number of months or years] and seeing [how many] different doctors before I had the right diagnosis.

ADD YOUR RESPONSE HERE

Q: HOW DID YOU GET LUPUS? IS IT CONTAGIOUS?

EXAMPLES

- Lupus is not contagious, not even through sexual contact.
- You can't "catch" lupus from someone or "give" lupus to someone.
- No one knows what causes lupus.
- Lupus and other autoimmune diseases do run in families.
- Experts think lupus may develop in response to certain hormones or environmental triggers (like sun exposure, having an infection, and stress).
- I think what triggers lupus to become active or worse in me is/are [list possible trigger(s)].

ADD YOUR RESPONSE HERE

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Q: CAN LUPUS BE PREVENTED?

EXAMPLES

- Right now, there’s no way to prevent the onset of lupus.
- There are a few known risk factors, but none of them can be prevented. They are: gender, age, ethnicity, and heredity.

ADD YOUR RESPONSE HERE

Q: HOW IS LUPUS TREATED?

EXAMPLES

- The goal of my treatment plan is to help me control my symptoms, keep my immune system from attacking my body, and protect my organs from damage.
- Since there are very few drugs specifically developed for lupus, medications originally developed for other conditions are used to treat lupus.
- Right now, I’m taking [list your medications here]. Sometimes I need to take additional medications to treat the side effects of these drugs, so I also take [list additional medications].
- Treating lupus can be difficult. It can take months – or even years – to find the right treatment plan.
- Lifestyle adjustments can really help people with lupus, especially getting enough rest and having the support of family and friends. The things that help me most are [list the top two or three].
- It’s important for me to avoid things that trigger the disease to become active, especially too much sun exposure, stress, infections, and smoking.

ADD YOUR RESPONSE HERE

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Q: CAN YOU DIE FROM LUPUS?

EXAMPLES

- Yes, lupus can be fatal. The leading causes of death are serious infections, heart attacks and related cardiovascular diseases, and kidney failure.
- Most people will live a normal lifespan if they follow their treatment plan and make any lifestyle changes that keep lupus from becoming active.

ADD YOUR RESPONSE HERE

Q: HOW DOES LUPUS MAKE YOU FEEL?

EXAMPLES

- Lupus has many different symptoms. It affects each person differently. The symptoms that affect me most are [list symptoms that most affect you].
- It’s hard to describe how much effort it takes for me to function every day because of the extreme fatigue, pain, memory loss, and medication side effects that I experience. [Or use your own examples].
- The worst thing for me is that lupus is so unpredictable. When I suddenly have a flare, it can be frustrating. [Or use your own examples].

ADD YOUR RESPONSE HERE

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Q: ARE YOU SURE YOU REALLY HAVE A DISEASE? YOU DON'T LOOK SICK.

EXAMPLES

- My doctor has offered to explain my condition to my family members and friends. I'd really like it if you'd come with me to my next appointment.
- I just wish I felt as good as I look!
- It's strange, isn't it, that I can be so sick on the inside and still look OK on the outside, but that's lupus.

ADD YOUR RESPONSE HERE

Q: WHY DON'T YOU TRY ALTERNATIVE TREATMENTS, LIKE [FILL IN THE BLANK]?

EXAMPLES

- I've worked with my doctor on a treatment plan, and I want to give it a chance.
- My doctor explained that herbal supplements and other unproven therapies can be dangerous when taken along with my prescribed medications, and could make my lupus worse.

ADD YOUR RESPONSE HERE

Q: WHY DON'T YOU CHANGE YOUR DIET TO [FILL IN THE BLANK]?

EXAMPLES

- There's been a lot of research done on this topic and currently there's no “special” diet for people with lupus. The recommended diet for me is the same one recommended for the general population.
- My current diet meets with my doctor's approval, so I'm going to stick with it.

ADD YOUR RESPONSE HERE

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EXAMPLE SPEECHES

EXAMPLE 1

Lupus is an autoimmune disease. That means my immune system is overactive and is causing inflammation and damage throughout my body. It's also a chronic illness, which means it's long-term. I was diagnosed last month, but now that I know more about lupus, I think I've had symptoms since I was a teenager. So far, lupus has affected my kidneys most of all. Right now, I'm taking corticosteroids and an antimalarial and infusions of a chemotherapy drug, all to keep my immune system from causing further damage. (31 seconds)

EXAMPLE 2

Lupus has so many different symptoms and it affects each person differently. The worst things for me are the joint pain and how tired I feel. It's hard to describe how much effort it takes me to function day-to-day. One of the most important things about living with lupus is to avoid things that trigger disease flares, like too much sun exposure and infections. I'm pretty good about those things, but lupus can flare without warning, and when I have a flare, it makes me feel really frustrated. Having the support of family and friends is so important. Right now, the things that help me most are my husband and kids pitching in to do the housework and switching to working part-time until I feel better. (33 seconds)

ADD YOUR SPEECH HERE

*I am newly diagnosed...
What should I ask my rheumatologist?*

INSTRUCTIONS:

This form is intended to remind you of some important questions that you may want to ask your rheumatologist if you are newly diagnosed and/or learning more about lupus. You can print or download this form and bring it to the doctor's office with you, for easy reference. You may want to ask these questions over the course of several visits. Feel free to mark up the form as you see fit, highlighting the questions you would like to ask and marking your notes below the questions your rheumatologist has answered. Please keep in mind that not all of these questions will apply to you and some questions may not be answered by your physician.

What symptoms should I expect as a part of this disease?

Under what circumstances should I notify my doctor or go to the emergency room?

Will other tests need to be done in the near future? How will my lupus be monitored?

What medications will I need to take? And what are the side effects?

How long before I start to see relief or know the medications are working?

How long will I be on these medications?

Will this disease affect my organs? And, if so, how do I prevent further damage?

Is lupus a fatal disease?

Which vaccines are safe for me to take?

What are some trusted websites where I can find more information? And do you recommend any good resources in which I can find material to help those around me understand?

Other questions you may want to ask now, or at a future visit:

MEDICATIONS

Will any of these medications interact with other medications that I am currently taking?

Will any of these medications affect other conditions that I may have?

Are there alternative therapies?

LIFESTYLE

Do I need to avoid the sun?

What should I use for sun protection?

What can I do to manage my fatigue?

Will I need to limit any of my normal day activities (e.g. exercise)?

Are there any exercises that may help?

Should I tell my employer that I have lupus?

(If it's difficult to work full or part-time) Will I need to apply for disability?

(If you smoke) How do I quit?

DIET/SUPPLEMENTS

Is there a diet I need to follow or certain foods I need to avoid?

Should I take vitamins or other dietary supplements?

FAMILY PLANNING

Will I have trouble getting pregnant?

Will my children develop lupus?

LUPUS CHECKLIST

If you have systemic lupus erythematosus (lupus), every symptom matters.

With lupus, it is important to discuss all of your symptoms – even the ones you might not associate with lupus. Please complete the Lupus Checklist below and discuss these symptoms with your rheumatologist at each appointment.

SYMPTOMS	I have had this symptom since my last doctor visit	I have had this symptom for: ____ hr/days/weeks	This is the first time I have had this symptom
<i>Example: Skin rash</i>	✓	3 weeks	<input type="radio"/>
Heart			
Chest pain	<input type="radio"/>	_____	<input type="radio"/>
Difficulty breathing	<input type="radio"/>	_____	<input type="radio"/>
Rapid and/or irregular heartbeat	<input type="radio"/>	_____	<input type="radio"/>
Lung			
Pain in the chest when deep breathing	<input type="radio"/>	_____	<input type="radio"/>
Eye			
Dry eyes	<input type="radio"/>	_____	<input type="radio"/>
Eye redness	<input type="radio"/>	_____	<input type="radio"/>
Some loss of vision	<input type="radio"/>	_____	<input type="radio"/>
Blood			
Bleeding and/or bruising easily	<input type="radio"/>	_____	<input type="radio"/>
Infections	<input type="radio"/>	_____	<input type="radio"/>
Muscles & Bones			
Muscle weakness	<input type="radio"/>	_____	<input type="radio"/>
Stiffness in joints	<input type="radio"/>	_____	<input type="radio"/>
Aching muscles	<input type="radio"/>	_____	<input type="radio"/>
Skin			
Skin rashes	<input type="radio"/>	_____	<input type="radio"/>
Sensitivity to sun or light	<input type="radio"/>	_____	<input type="radio"/>
Mouth or nose sores	<input type="radio"/>	_____	<input type="radio"/>
Hair loss	<input type="radio"/>	_____	<input type="radio"/>
Brain			
Seizures	<input type="radio"/>	_____	<input type="radio"/>
Headache and/or dizziness	<input type="radio"/>	_____	<input type="radio"/>
Memory problems or confusion	<input type="radio"/>	_____	<input type="radio"/>
Sad thoughts	<input type="radio"/>	_____	<input type="radio"/>
Weakness/numbness on one side (for example, one arm weak or numb)	<input type="radio"/>	_____	<input type="radio"/>
Kidney			
Swelling of legs and/or feet	<input type="radio"/>	_____	<input type="radio"/>
Frothy and/or bloody urine	<input type="radio"/>	_____	<input type="radio"/>
General			
Fatigue	<input type="radio"/>	_____	<input type="radio"/>
Fevers	<input type="radio"/>	_____	<input type="radio"/>
Weight change	<input type="radio"/>	_____	<input type="radio"/>
Poor appetite	<input type="radio"/>	_____	<input type="radio"/>
Other			
Other 1: _____	<input type="radio"/>	_____	<input type="radio"/>
Other 2: _____	<input type="radio"/>	_____	<input type="radio"/>



This checklist is neither a diagnostic tool nor a complete list of all possible lupus symptoms. Be sure to talk to your doctor about all of your symptoms.

TALK TO YOUR RHEUMATOLOGIST ABOUT YOUR LUPUS SYMPTOMS.

This checklist can help you at your next appointment.

Step 1: Complete the checklist.

Step 2: Use the notes space below to prepare for each appointment. Regular appointments are often brief so it's important to write down any questions you may have for your rheumatologist ahead of time. Keeping questions brief and focused can help you make the most of your time together.

Step 3: Consider bringing a close friend or family member along with you to your appointment to support you and act as an extra set of ears. Give that person the job of writing down the information and answers to your questions that your doctor provides.

Step 4: At each appointment, discuss any changes in your health (even the ones you don't think are related to your lupus) with your rheumatologist, as some symptoms may indicate organ damage.

If you have more than one doctor, make sure they are all aware what the others are recommending to help ensure there are no conflicts in your health management. Consider bringing copies of your most recent appointment notes to each doctor visit.

Help your doctor help you. Use this checklist to capture your lupus symptoms and bring it to each appointment.

