

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

HOW TO EXPLAIN LUPUS TO OTHERS

Developing Your “About Lupus” Speech

- 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

HOW TO EXPLAIN LUPUS TO OTHERS

Developing Your "About Lupus" Speech

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

HOW TO EXPLAIN LUPUS TO OTHERS

Developing Your “About Lupus” Speech

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’s only one drug 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

HOW TO EXPLAIN LUPUS TO OTHERS

Developing Your “About Lupus” Speech

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

HOW TO EXPLAIN LUPUS TO OTHERS

Developing Your “About Lupus” Speech

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

HOW TO EXPLAIN LUPUS TO OTHERS

Developing Your “About Lupus” Speech

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