

Plain
Talk
About
Lupus
and
Key
Words



START

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Plain Talk About Lupus and Key Words

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This booklet was written so that we can begin to use the same words when we talk about lupus. Please share it with friends.

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Plain Talk About Lupus

Plain Talk About Lupus gives the everyday meaning of medical words that are used when talking about lupus. Many of the words and phrases used by medical people are special to their work and may feel like another language to us. We hope this booklet will help you when you read or talk to people about lupus.

What will you find in this booklet?

First, we talk about lupus.

Next, we list words from A to Z. These words are often found in patient booklets and hand-outs. We give the meaning of each word and try to use plain English. We also give a sentence for each word.

Finally, at the end of this booklet, we leave space for new words, phrases and places you can call for more information.

Common Questions

If you have lupus, you probably have many questions.

How will I look and feel?

You will look and feel well most of the time. The people you live with and work with may have trouble understanding that you have a disease. Many people do not understand that some diseases are quiet for a while and flare up for a while.

How long will this last?

Lupus is a chronic disease. A chronic disease is with you always. It cannot be cured. BUT . . . chronic diseases can be managed.

Lupus is not a simple disease. You cannot take a pill and make it go away. In addition, lupus is unusual because it can seem like other diseases. Lupus can be a bit different for every person who has it.

Can anything be done?

The good news is that you can get help to treat and to manage your lupus.

Take Care and Take Action

Experts talk about four basic care and action steps:

- **Get the facts.**
You need to know about lupus in order to take care of yourself.
- **Have a medical check-up on a regular basis.**
This type of disease changes over time and with life events. You can take better care when you note and act on changes.
- **Get support to help you with the emotional side of illness.**
Illness can be hard on our minds and on our emotions. Managing a disease is hard work and we need to be sure that we have the support we need.
- **Move more and eat better.**
You will feel better if you are active and eat well. This helps you build the strength and energy you need to deal with illness.

Get the facts about lupus and about lupus care

Lupus is a disease of the immune system. There are two main types of lupus:

1. The first type of lupus is called **systemic lupus erythematosus**. It is also known as SLE. SLE may affect several body systems. These body systems include the skin, joints, kidneys, lungs, heart and the nervous system.
2. Another type of lupus is called **discoid lupus**. It is also called cutaneous lupus. Discoid lupus affects the skin. About 15 percent of people with lupus have discoid lupus.

Anyone can get lupus. Here are some facts about lupus:

- 9 out of 10 people who have lupus are women.
- Lupus is more common in Hispanic women and in African American women than in European American women.
- African Americans and Hispanics get the disease at an earlier age and may have more symptoms. Researchers do not know why this is so.

A doctor is the best source of information. You may want to talk with a doctor who is a lupus expert. A rheumatologist is a doctor who treats people with lupus.

Ask if your hospital has a patient education library. These libraries often have staff that can help you get the facts you need about lupus. Your neighborhood librarian could also help you find good web sites.

Have a regular medical check-up

Talk with your doctor

When you manage a chronic disease like lupus, you will want to be sure to see your doctor on a regular basis—even when you are feeling well.

Your doctors and others on your medical team can help you learn about lupus and how to take care of yourself.

People with a chronic disease learn to pay attention to changes in their bodies. You will want to talk with your doctor about any changes and symptoms.

Make a plan together

You and your doctor can work together to find the best way to treat all of your symptoms.

Your treatment will depend on your symptoms.

Over time, you may see special doctors. For example:

- You might see someone who is trained in the care and treatment of people's kidneys. This person is called a nephrologist.
- You might see someone who is trained in the care and treatment of people's skin. This person is called a dermatologist.

Get support to help with the emotional side of illness

A chronic disease like lupus can be stressful and hard on your spirit and on your emotions. You might think that your friends, family and co-workers do not understand how you feel.

You may feel unhappy because you can't do as much as you did before you had lupus. Sadness and anger are common reactions.

People with lupus suggest some helpful hints . . .

- Stay involved in social activities. Keep up to date with your friends. Let them know that you want to be involved even though you may not be able to do everything.
- Be good to yourself. Take care of your spiritual side. Many people use prayer, relaxation exercises, or meditation.
- Decide what is most important. Spend your time on those important activities and with those people who mean the most to you.

More hints . . .

- Consider joining a support group or seeing a counselor. Counseling is help from a professional who will listen to you and help you develop a plan of action.
- Be sure to ask for help when you need it.
- Share how you are feeling with your family and friends. You can help them understand that the disease sometimes flares up and causes problems.

Move more and eat better

In general, you will need to be as strong and healthy as you can. Moving more and eating better will help you.

Move More

- An exercise program helps people with lupus. Exercise will give you more energy for doing the things you need and want to do. Exercise will help you build strong muscles and flexible joints. This will make your daily tasks easier.
- A physical therapist can help you plan an exercise program. You can change your exercise program depending on how you feel each day.
- Everyone needs to exercise. Exercise can help to improve and maintain your health.

Eat Better

- You might need to take special care about what you eat. This is very important if you have kidney problems, osteoporosis, or take a lot of steroid medicine.
- A nutritionist can help you decide on a meal plan that fits your needs and is good for you.
- Healthy eating habits are very important. Overall, good eating habits will increase your energy and help you maintain your weight.

Lupus Words from A to Z

This section of the booklet is called a glossary. A glossary is made up of words and their meanings. This glossary lists words people use when they talk or read about lupus. The words are in A to Z order.

First, we show how to say the word. Next, we give the meaning of the word. Finally, we use each word in a sentence.

How to Say the Word

You will see parenthesis that look like this () after each word. Here between the () we sound out the word. You will note that some letters are in capital letters. This part of the word is said with a strong beat.

For example, the full name for SLE is Systemic Lupus Erythematosus. This is quite a mouthful. We show how to say these words. The first word, *systemic*, is written as *sis TE mik*. This helps you say the word out loud.

The Word in a Sentence

We use made-up names in the sentences. You may notice that Linda and Susan have lupus and see Dr. Santos for their care. Dan has lupus and sees Dr. Lin for his care. Each example sentence begins with a ♦.

Key Words

Lupus Words from A to Z

A

Acute

(a KYOOT)

Rapid or sudden start of symptoms. It's sometimes painful and serious.

- ◆ The winter flu is an **acute** illness because it starts suddenly.

Aerobic exercise (a RO bik EK sur size)

Exercise that helps the heart stay healthy and work better.

- ◆ Gene walks fast every day for **aerobic exercise**.

Aggravate

(AG ra vate)

Make worse.

- ◆ Linda **aggravates** her lupus when she is in the sun.

Alopecia

(al oh PEE she a)

More than a normal amount of hair loss.

- ◆ Linda experienced **alopecia** during her last lupus flare.

Alternative (all TUR na tiv)

Another choice or a different way.

- ◆ Susan runs on a treadmill indoors as an **alternative** to running outside in the sun.

Anemia

(a NEE mee a)

A low blood count that can make you tired and short of breath.

- ◆ Mary sometimes has trouble climbing stairs because her **anemia** makes her feel very weak.

- Annual** (AN yoo ul)
Every year.
◆ Sonia always plans her **annual** breast exam the day after her birthday so she doesn't forget.
- Antibody** (AN tee bod ee)
Proteins in the blood that fight different infections.
◆ The flu vaccine causes your body to make its own **antibodies** that will fight the flu.
- Antibiotics** (an tee by AH tiks)
Drugs that kill or slow the growth of germs.
◆ Tony took **antibiotics** to treat his ear infection.
- Anti-inflammatory** (an tee – in FLAM a tor ee)
Something that reduces swelling, heat and pain. It is usually a medicine.
◆ Mary takes **anti-inflammatory** drugs for her arthritis.
- Arthritis** (ar THRY tis)
A problem with the joints that causes swelling, pain, heat and a sense of stiffness.
◆ Mary finds it hard to pick things up when her **arthritis** is bad because of the pain and swelling in her hands.

Atherosclerosis (a theer oh sklur OH sis)

A disease that causes the blood vessels to harden and narrow. This can cause heart attacks and strokes.

◆ Dr. Lin told Dan that he does not have **atherosclerosis**. Dan's blood vessels are not narrow or hard.

Autoimmune disease (au to im MUNE di ZEEZ)

A disease of the immune system that makes your immune system attack your own body.

◆ Linda's kidneys are damaged because of her **autoimmune disease**.

B

Bacteria (bac TEER ee a)

Germs.

◆ **Bacteria** got into the wound on Robert's hand and caused an infection.

Benign (be NINE)

Not a danger.

◆ Tony was happy to learn that his tumor was **benign**. He was happy that it was not a danger to his life.

Bursitis (bur SY tis)

Inflammation of a bursa. A bursa is like a tiny pillow filled with fluid between the tendon and the bone. It is not arthritis because it is outside the joint.

◆ Mary's shoulder **bursitis** is very painful. She cannot lift her arm to comb her hair easily.

Butterfly rash (BUH tur fly rash)

A dry red rash on the cheeks and across the nose. It is a sign of lupus.

- ◆ Linda sometimes wears makeup when she has a **butterfly rash**.

C

Cardiovascular (kar dee oh VAS kyoo lar)

Having to do with the heart and blood vessels.

- ◆ Linda has a healthy **cardiovascular** system because she exercises everyday.

Cartilage (KAR tuh lij)

The smooth covering on the end of bones.

- ◆ Gene's arthritis damaged the **cartilage** in his fingers over the years.

Cataracts (KAT a rakts)

A clouding over the lens of the eye. This can make it hard for people to see.

- ◆ Dan goes to the eye doctor every two years to check for **cataracts**. Steroids can cause **cataracts** if you take them for a long time.

Chronic (KRAH nik)

Does not go away. Long term.

- ◆ Lupus is almost always a **chronic** disease. Linda will have it for the rest of her life.

- Clinical** (KLI ni kal)
Work or studies in a medical setting that involve patients.
◆ Linda is in a **clinical** study of a new treatment for lupus.
- Comprehensive** (kom pree HEN siv)
Complete. Covers everything important.
◆ Sonia has a **comprehensive** medical exam once a year.
- Condition** (kon DI shun)
A medical problem or disease.
◆ Dr. Lin told Dan that there was a new treatment for his **condition**.
- Conditioning** (kon DI shun ing)
Physical training to improve how long you can exercise and how strong you are.
◆ Susan learned **conditioning** exercises from her physical therapist.
- Contagious disease** (kon TAY jus di ZEEZ)
An illness that can spread from person to person.
◆ Lupus is not a **contagious** disease, but colds are.
- Control** (kon TROLE)
To manage, to have power.
◆ Linda **controls** her lupus by taking medicines and following her treatment plan.

Cure

(kyoor)

To completely get rid of or stop a disease.

- ◆ Linda took antibiotics to **cure** her infection.
- ◆ Today there is no **cure** for lupus.

Cushingoid (KUSH ing oyd)

Signs and symptoms of high doses of corticosteroids. Some signs are weight gain around the face, as well as the upper back and very thin skin.

- ◆ Dr. Santos told Linda that her face looked a bit larger because her medicine caused **cushingoid** symptoms.

Cutaneous (kyoo TAY nee us)

Having to do with the skin.

- ◆ Dr. Jones can see the psoriasis on Robert's elbows. It is a **cutaneous** disease and can be seen on the skin.

D

Deformity (dee FOR mi tee)

A change from the normal shape.

- ◆ Gene had to buy larger gloves because his arthritis caused some **deformity** of his hands.

Degenerative disease (dee JEN ur a tiv di ZEEZ)

A disease that causes damage over time.

- ◆ The arthritis in Tony's knees has gotten worse over the years because of a **degenerative disease** called osteoarthritis.

Dermatologist (dur ma TAL oh jist)

A doctor and specialist who treats skin problems.

◆ Robert goes to a **dermatologist** for his psoriasis.

Deteriorate (dee TEE ree oh rate)

Get worse.

◆ Sonia now wears glasses because her eyesight has **deteriorated**.

Diabetes (dy a BEE tis)

Diabetes is a disease that makes your body unable to make or use insulin. Insulin makes sugar into energy to keep you alive.

◆ Susan is very careful not to eat foods with lots of sugar because she has **diabetes**. Susan has **diabetes** because she takes high doses of steroids for her lupus.

Diagnose (dy ag NOHS)

To figure out what is causing health problems.

◆ Dr. Santos was able to **diagnose** Linda's lupus after seeing more symptoms over time.

Diagnosis (dy ag NO sis)

A condition, disease or a medical answer.

◆ Dr. Lin gave Dan a **diagnosis** of lupus after a check-up, some tests and hearing Dan's story.

Discoid (DYSK oyd)
Shaped like a disk or round circle.
◆ The round red circles on Mary's face were a sign of **discoid** lupus.

Dose (dohs)
An amount of medicine.
◆ Dan takes one 10mg **dose** of steroids every morning. If his lupus is acting up he may need a larger **dose**.

E

Effective (ee FEK tiv)
Works well.
◆ Linda wears a hat with a big brim. This is an **effective** way to keep the sun off her face.

Environment (en VY ro ment)
The place where we live. This includes the inside, such as our homes and workplaces. This also includes the outside, such as air, water and weather.
◆ The **environment** can cause an illness. It can also make symptoms better or worse.

Episode (EP i sode)
A specific event with a beginning and an end.
◆ Susan had a short **episode** of chest pain.

Erosions (ee RO zhuns)
Small pits or holes in the cartilage or the bone.

◆ Dr. Jones looked at the x-ray and saw **erosions** in Robert's hip.

Erythematosus (er ry THEM a toe sis)
Red rash on the face. This word is also in the name for a kind of lupus called systemic lupus erythematosus or SLE.

◆ Susan has systemic lupus **erythematosus**. Her face rash is red when her lupus is in flare.

Exert (eg ZERT)
To push or work hard.

◆ Susan **exerts** herself when she walks up an extra flight of stairs.

F

Fast (fast)
To go without any food or drink.

◆ Dan was told to fast for 12 hours before his blood test.

Fatigue (fa TEEG)
A tired or weak feeling of the whole body.

◆ Dan felt a sense of fatigue and so he rested when he got home.

Flare (flare)
A period of time when symptoms of a disease are worse.

◆ Linda had a **flare** of her lupus for two months.

Flexibility (FLEK suh bil a tee)
Able to move with ease. Muscles and joints that stretch easily.
◆ Dr. Lin said that exercise would increase Dan's **flexibility**.

G

Glaucoma (glaw KO ma)
An eye disease where there is increased pressure from the inside of the eye. Too much pressure over time can lead to blindness.
◆ Dan goes to the eye doctor every two years to check for **glaucoma**. He knows that **glaucoma** can be a side effect of high doses of steroids.

H

Hemodialysis (hee mo dy AL uh sis)
A process that uses a machine to clean the blood. This process removes harmful substances from the blood when the kidneys cannot do this.
◆ Susan goes for **hemodialysis** three times a week because her kidneys were damaged by lupus.

Hormones (HOR mones)

Natural chemicals made by your body. Scientists can also make them. These chemicals are important for many body functions.

- ◆ Cortisone is a **hormone** made by your body. Prednisone is the pill form of this **hormone**.

I

Immune System (im MUNE sis tum)

The part of your body that fights against germs and other intruders.

- ◆ Robert's **immune system** went right to work to fight germs when he got a deep cut.

Infection (in FEK shun)

An illness that is caused by germs.

- ◆ Robert taught his son how to take care of a cut so he will not get an **infection**.

Inflammation (in fla MAY shun)

Swelling, redness, heat and pain. This happens when parts of your body are hurt or react to illness. The body sends extra blood cells to the place that is hurt.

- ◆ Steroid medicines reduce **inflammation**.

Infusion (in FYOO zhun)

A way to give fluids or medicine directly into a vein.

- ◆ Linda had an **infusion** of Cytoxan because her lupus was in flare.

Inherit

(in HER it)

Something that is passed on in a family. Happens to members of a family more than would happen by chance in the public. Also called familial.

◆ Dr. Santos explained to Linda that her lupus can be **inherited**. Linda has three people in her family who have lupus.

Inhibit

(in HI bit)

To stop or hold back something.

◆ Susan takes a medicine to **inhibit** her immune system.

Injection

(in JEK shun)

To give medicine by a needle under the skin, into a muscle or into a joint.

◆ Robert gives himself an insulin **injection** every day.

Internal organs (in TER nal OR gun)

The inside parts of your body, such as heart, lungs, kidneys and liver.

◆ Lupus can harm some **internal organs**.

Intravenous (in tra VEE nus)

Putting fluids or medicine into a vein by using a needle.

◆ Mary receives an **intravenous** medicine from the visiting nurse.

Itis

(eye tyss)

These letters are found at the end of a word. It means swelling or inflamed in the Greek language. *Arth* is a Greek word meaning joint. When you add *itis*, this word now reads *arthritis*.

Here are other examples:

- ◆ Nephritis means inflammation of the kidney.
- ◆ Myocarditis means inflammation of the heart muscle.

J

Joint

(joynt)

The place where two bones come together. This is where we can bend and move.

- ◆ Tony has trouble buttoning his shirt when his finger **joints** are stiff.

K

We don't have any "K" words, but you may.

Write your "K" words here:

L

Ligament (LIG a ment)
A strong band that holds a joint together.
◆ Tony tore two knee **ligaments** when he played football.

Localized (LO ka lized)
In a small area or only in one place.
◆ Susan's rash was **localized** to her face. She did not have it anywhere else.

Long-term (long – term)
For a long time, more than just weeks or months.
◆ Sonia's mother needed **long-term** care after she broke her hip.

M

Manage (MAN ej)
To control or direct.
◆ Dan's health care team taught him to **manage** his lupus with medicine and good planning.

Medication (med I KAY shun)
A medicine or drug to treat an injury, illness or disease. Some must be prescribed by a doctor. Others can be bought in a drug store over the counter.
◆ Linda gets her lupus **medications** at her local drug store.

- Mobility** (mo BIL a tee)
Able to move around.
◆ Surgery improved Tony's **mobility**. He is now able to walk to the store.
- Moderate** (MA dur it)
Between mild and serious; between weak and strong.
◆ Linda takes time to rest when she has **moderate** symptoms.
- Monitor** (MA ni tur)
To watch and check something carefully for changes.
◆ Dr. Santos sees Linda every two months to **monitor** her lupus.

N

- Narcotic** (nar KA dik)
A strong medicine or drug that takes away pain. It can make you sleepy and your body can grow to need it.
◆ You should not drive when you take a **narcotic** because you may fall asleep at the wheel.
- Neurologic** (nur a LA jik)
Having to do with the nervous system. The nervous system includes nerves, the spinal cord and the brain.
◆ One sign of a **neurologic** problem may be a constant feeling of pins and needles.

Nutrition (noo TRI shun)
Food. Healthy eating to help your body grow and repair itself.
◆ A healthy diet provides **nutrition** for your body.

0

Occasionally (oh KAY zhun a lee)
Sometimes, not often.
◆ Linda **occasionally** forgets to take her medicine but she remembers most of the time.

Occupational Therapist (ah kyoo PAY shun ul THEHR a pist)
A professional who helps people who are ill or injured learn better ways to do everyday activities such as bathing, dressing, cooking, eating, or driving. Also known as an OT.
◆ Janet's **occupational therapist** taught her how to set up her kitchen and office space to lessen the stress on her hands.

Orthopedic Surgeon (or tho PEE dik sur jun)
A doctor who operates on bones and joints.
◆ Tony's **orthopedic surgeon** has done many operations to replace damaged joints.

Osteonecrosis (ah stee oh ne KRO sis)

Death of a bone or part of a bone from not getting enough blood. It can be caused by many diseases and from steroid use.

- ◆ Susan had a lot of pain in her hip. Dr. Santos told her that she had **osteonecrosis** because she had taken steroids for many years.

Osteoporosis (ah stee oh por OH sis)

Thin and weak bones which break easily.

- ◆ **Osteoporosis** is common in older women and in people who need to take steroids.

P

Pericarditis (pare I kar DY tis)

A condition when the covering of the heart is inflamed.

- ◆ Susan's chest and neck hurt when she was lying down. Dr. Santos told her that she had **pericarditis** and that this can happen to people with lupus.

Peritoneum (pare I to NEE um)

Lining of the abdomen or belly.

- ◆ Janet had stomach pains that were worse when she sneezed or coughed. The doctor told her that the pain was caused by inflammation of her **peritoneum**.

Permanent (PUR ma nent)
Never goes away.
◆ Mary's arthritis caused **permanent** joint damage. Only surgery can help.

Persistent (pur SIS tent)
Lasts for a long time.
◆ Linda had a **persistent** cough for two months and went to the doctor to find out why.

Pharmacist (FAR ma sist)
A trained person who prepares medicine. This person makes sure you get the right kind and amount of medicine that your doctor ordered.
◆ The **pharmacist** filled Linda's prescription.

Photosensitive (fo to SEN si tiv)
Sensitive to sunlight. These reactions can cause rashes, fevers or a flu-like feeling.
◆ Dan always wears sunscreen when he walks outside because the medicine he takes for his lupus makes him **photosensitive**.

Physical Therapist (fi si kal THEHR a pist)
A trained professional who helps patients learn ways to decrease their pain. Also known as a PT. A PT helps patients increase and maintain their motion and strength.
◆ The **physical therapist** taught Janet how to change her exercise program when her lupus was in flare.

- Platelet** (PLATE let)
Cells in the blood that help stop bleeding.
◆ Dan's **platelet** numbers are low. He gets a lot of nosebleeds.
- Pleurisy** (PLUR I see)
Inflammation of the covering of the lungs.
This can cause pain in the chest.
◆ Linda had a lot of pain when she took a deep breath.
◆ Dr. Santos told her that she had **pleurisy** from her lupus.
- Prescription** (pre SKRIP shun)
Written directions from your doctor to the pharmacist about your medicine. Also known as "Rx" or a "script."
◆ Susan can only get prednisone with a **prescription** from her doctor.
- Prevent** (pre VENT)
To keep from happening.
◆ Good health habits can help **prevent** heart disease or even cancer.
- Progression** (pro GRESH un)
To move forward for better or for worse.
◆ New medicines can slow down the **progression** of lupus.

Psychiatrist (sy KY a trist)

A doctor who treats people for emotional problems or mental illness.

- ◆ The **psychiatrist** helped Linda see that it made sense for her to be upset. Linda’s visits to the **psychiatrist** helped her to cope with her lupus and to feel better.

Q

We don’t have any “Q” words, but you may. Write your “Q” words here:

R

Radiologist (ray dee AL oh jist)

A doctor who looks at and studies x-rays and other images to diagnose health problems.

- ◆ The **radiologist** looked at the x-ray of Janet’s hip to see if she had any signs of bone problems.

Raynaud's Syndrome (ray NODES SIN drome)

A medical problem that causes the blood vessels in the fingers and toes to narrow and let less blood through when they are cold. The fingers and toes become pale and feel uncomfortable.

◆ Janet always wears gloves when she goes out in the cold because she has **Raynaud's Syndrome**.

Reaction (ree AK shun)

A response. An action that happens because of another event.

◆ Dan had a rash and Dr. Lin said it was a **reaction** to his new medicine.

Regular (REG yoo lar)

Usual, normal.

◆ Linda walks three times a week on a **regular** schedule.

Relief (ree LEEF)

Feeling better.

◆ A warm shower gives Gene **relief** from his morning stiffness.

Remission (ree MI shun)

A period of time when a disease is not active.

◆ Linda's lupus has been in **remission** for six months.

Rheumatologist (roo ma TAL oh jist)

A doctor who specializes in diagnosing and treating problems of the immune system, joints and bones.

- ◆ Mary's family doctor was not sure of the cause of her joint pain, so he sent her to a **rheumatologist**.

S

Schedule (SKEH jyool)

A plan. Planning a time to do something.

- ◆ Linda's nurse, Ms. Green, helped her make a **schedule** so she would know when to take her pills.
- ◆ Linda used her kitchen calendar to **schedule** her appointments.

Seizure (SEE zhur)

A sudden attack in the brain. A person can black out and have uncontrolled movements.

- ◆ Dan can't drive because he sometimes has **seizures**. Doctor Lin told him that his **seizures** were caused by his lupus.

Sensitive (SEN si tiv)

Easily hurt or damaged.

- ◆ Susan's skin is very **sensitive** to the sun because of her lupus. She needs to wear very strong sunscreen.

Severe (suh VEER)

Very serious or very bad.

- ◆ Janet stayed out of work because of **severe** fatigue.

- Side effect** (SIDE e fect)
A reaction caused by a medicine.
◆ Susan told her friends that she gained weight as a **side effect** of her steroids.
- Sign** (sine)
A medical problem that can be seen or noticed by a doctor.
◆ A butterfly rash is often a **sign** of lupus.
- Sjogren's Syndrome** (SHOW grins SIN drome)
A medical problem that causes the eyes and mouth to be dry.
◆ Robert puts medicine drops in his eyes three times a day because he has **Sjogren's Syndrome**.
- Soreness** (SORE ness)
Hurt, pain or ache.
◆ Linda has **soreness** in her wrists from gardening.
- Spasm** (SPAZ um)
A sudden tightening of muscles.
◆ Robert had a muscle **spasm** in his back after painting his son's room.
- Stable** (STAY bul)
No change. Stays the same.
◆ Dr. Santos told Linda that her lupus is **stable** since her symptoms have not gotten worse and she is feeling well.
- Stamina** (STA min a)
Endurance. Able to be active without feeling tired or exhausted.
◆ Gene does not have enough **stamina** to work full-time.

- Steroid** (STER oyd)
Medicines used to decrease inflammation.
◆ Corticosteroids are the steroids used to treat lupus. Hydrocortisone and prednisone are examples of steroids.
◆ Dr. Lin increases Dan's **steroid** dose when his lupus is very active.
- Stress** (stress)
Physical, mental or emotional tension or strain.
◆ Linda notices that there is a lot of **stress** at work just before the holidays. This could cause her lupus to flare up.
- Supplement** (SUP luh ment)
To complete or add to.
◆ Gene takes vitamins to **supplement** his diet.
- Suppress** (sa PRES)
To hold back.
◆ Dr. Santos gave Linda steroids because they **suppress** the immune system.
- Surgery** (SUR ger ee)
An operation.
◆ Tony walked better after his knee **surgery**.
- Susceptible** (sus SEP tuh bul)
More open to.
◆ Susan's medicine helps her lupus. But, the medicine also makes her more **susceptible** to infection.

- Swelling** (SWEL ing)
 An increase in size because of fluid.
 The body's response to injury or illness.
 ♦ Sonia put ice on her knee to reduce the **swelling**.
- Symptom** (SIMP tum)
 A feeling or physical sign that may be due to an illness or disease.
 ♦ Tony felt stiff every morning. This was his first **symptom** of arthritis.
- Syndrome** (SIN drome)
 A set or pattern of symptoms that often go together.
 ♦ Janet has Raynaud's **Syndrome**.
- Systemic** (sis TE mik)
 In all parts of the body.
 ♦ Lupus is a **systemic** disease because it involves the joints, skin, kidneys, lungs and other body parts.
- Systemic Lupus Erythematosus** (sis TE mik LOO puss er ri THEM a toe sis)
 A disease of the immune system. See page 4 for more information.

I

- Taper** (TAPE ur)
 To slowly lower or cut down; to make smaller.
 ♦ Janet was sure to **taper** her dose of steroids over two weeks. She knew that it was dangerous to just stop taking her steroids.

Temporary (TEM pur ar ee)
Does not last. Only for a short period of time.

- ◆ Dan needed to take a nap every afternoon. He knew this was only **temporary**.

Therapy (THEHR a pee)
Action to help a disease, illness, or injury.

- ◆ Mary walks every day as **therapy** for her arthritis.

Treat (treet)
To give care.

- ◆ Dr. Santos **treats** Linda for her lupus.

Treatment (TREET ment)
The action or medicine used to take care of a disease or injury.

- ◆ Linda's **treatment** for her lupus includes medicine and exercise.

U

Ulcer (UL sur)
An open sore that can be inside or outside of the body.

- ◆ Linda has to take medicine to help her stomach **ulcer** heal.

V

Vague

(vayg)

Unclear. Not for sure

◆ Sonia's symptoms were **vague** so Dr. Smith could not make a clear diagnosis.

We don't have any words for the following letters, but you may. Write other words here:

W

_____	_____
_____	_____

X

_____	_____
_____	_____

Y

_____	_____
_____	_____

Z

_____	_____
_____	_____

Abbreviations

FDA	Food and Drug Administration. The FDA is a government agency that makes rules about food and drugs to keep them safe.
IV	Intravenous. IV means into the vein.
mg	Milligram. Mg is a unit of weight. It is used as an amount of medicine.
RA	Rheumatoid Arthritis (ROO ma toyd ar THRY tis)
SLE	Systemic Lupus Erythematosus. (sis TE mik LOO puss er ri THEM a toe sis)
SPF	Skin Protection Factor SPF is represented as a number. This number tells you the strength of a sunscreen product. For example, an SPF of 30 offers good protection.
UVA and UVB	Ultraviolet rays A and ultraviolet rays B. Both UVA and UVB rays are parts of sunlight.

Common Tests

ANA Antinuclear Antibody. An ANA is a test for abnormal antibodies.

Antiphospholipid Antibody

This antibody is involved in blood clotting. More blood clots form when this measure is high.

Bone Density Test

Bone density is a test of how solid and how strong your bones are.

Complement Proteins

Proteins in the blood that fight infections. This test measures levels of these proteins in the blood. This test is also used to see how severe the disease is or to see if a treatment is working.

EKG Electrocardiogram. An EKG is an electric recording of the heart.

ESR Erythrocyte (ir RITH ro cite) Sedimentation Rate ESR is a blood test.

LFT's Liver function tests. The general term for a group of tests that check how your liver is working.

Hematocrit The percent of blood that is made up of red blood cells.

X-Ray A picture of the bones and other parts inside of the body.

Places to Go for Care and Testing

Cardiology (kar dee AL oh gee)

The medical department that treats heart problems.

Dermatology (dur ma TAL oh gee)

The medical department that treats skin problems.

Nephrology (nef RAL oh gee)

The medical department that treats kidney problems.

Neurology (nur AL oh gee)

The medical department that treats problems of the brain and nervous system.

Nutrition (noo TRI shun)

The medical department that focuses on food and diet.

Occupational Therapy (ah kyoo PAY shun al

THEHR a pee)

Part of the rehabilitation department. This type of therapy helps patients learn easier ways to do every day activities. Also known as OT.

Orthopedics (orth oh PEE diks)

The medical department that treats bone and joint problems — usually with surgery.

Physical Therapy (fi si kal THEHR a pee)

Part of the rehabilitation department. This type of therapy helps patients learn ways to decrease their pain and to increase and keep their motion and strength. Also known as PT.

Podiatry (po DY a tree)

The medical department that treats problems of the feet.

Psychiatry (sy KY a tree)

The medical department that treats people with mental or emotional problems.

Pulmonology (pull muh NAL oh gee)

The medical department that treats lung problems.

Radiology (ray dee AL oh gee)

The medical department that uses x-rays and other images to help diagnose medical problems.

Rheumatology (roo ma TAL oh gee)

The medical department that treats problems of the immune system, joints and bones.

Places To Call For More Information

YOUR LOCAL NUMBERS

NATIONAL RESOURCES

Lupus Foundation of America

Mailing Address: 2000 L St. NW, Suite 710
Washington, DC 20036
Telephone Number: 1-202-349-1155
Magazine: *Lupus Now*
Internet Address: www.lupus.org

National Arthritis Foundation

Mailing Address: P.O. Box 7669
Atlanta, GA 30357-0669
Telephone Number: 1-800-568-4045 (free call)
Magazine: *Arthritis Today*
Internet Address: www.arthritis.org

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Information Clearinghouse

Mailing Address: National Institutes of Health (NIH)
1 AMS Circle
Bethesda, MD 20892-3675
Telephone Number: 1-877-226-4267 (free call)
Internet Address: www.niams.nih.gov

Alliance for Lupus Research

Mailing Address: 28 West 44th Street
Suite 1217
New York, NY 10036
Telephone Number: 1-800-867-1743 (free call)
Internet Address: www.lupusresearch.org

Lupus Clinical Trials Consortium, Inc. (LCTC)

Mailing Address: 221 East 48th Street
Ground Floor
New York, NY 10017
Telephone Number: 1-212-593-7227

Lupus Research Institute

Mailing Address: 149 Madison Avenue
New York, NY 10016
Telephone Number: 1-212-685-4118
Internet Address: www.lupusresearchinstitute.org

Rheuminations, Inc.

Mailing Address: 221 East 48th Street
Ground Floor
New York, NY 10017
Telephone Number: 1-212-593-5180
Internet Address: www.dxlupus.com

“Use the smallest word
that does the job.”

—E.B. White

This booklet is available
for downloading at
www.hsph.harvard.edu/healthliteracy.

