



LUPUS
FOUNDATION
OF FLORIDA

Living Well

with

Lupus

Lupus Foundation of Florida

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The Lupus Foundation of Florida...

Has been serving Floridians affected by lupus since 1979. The Foundation provides support groups, education, referrals, advocacy and hope. Part of the Lupus Research Institute Coalition, we help fund novel research as we move closer to the goal of "Life without Lupus." For many years, four lupus organizations have all been working to cure lupus, but sadly, not working together! In 2015, three of these organizations began a historic merger! The Lupus Research Institute, the Alliance for Lupus Research and the SLE Foundation are coming together as one! The Lupus Foundation of America remains a separate entity.

Disclaimer

Lupus is a potentially serious autoimmune disease that requires treatment by a rheumatologist and possibly other doctors depending on the severity of the disease. This booklet does not replace medical care. The booklet is intended to give lupus patients tools to better manage lupus in conjunction with their medical professionals.

After the Diagnosis

You have been diagnosed with lupus. For most people the diagnostic process has been a journey involving several years and several doctors. You may be relieved to finally have confirmation that your symptoms are not "all in your head" and that you have a real disease and that disease has a name. For a few, the diagnosis may have been swift and dramatic.

Either way you are probably wondering what's next. Most lupus patients have three major questions. Will lupus kill me? Is lupus progressive? Will I become disabled and dependent? If you ask your rheumatologist these questions, the answer is, "I don't know."

Your rheumatologist is not stupid nor is your rheumatologist avoiding the questions. Lupus is very unpredictable. While lupus is often mild to moderate, it can become life-threatening at times. Periods of little or no disease activity are called remissions. Periods of disease activity are called flares. No one can predict when flares will come or how long they will last. Information and good self-management can minimize the impact of lupus on your life. This booklet is a good starting point

Chronic Illness

When it comes to illness and injury, most of us have the model of acute illness in our minds. Think about a broken bone, appendicitis or strep throat. The onset, diagnosis and treatment are clear. You get sick or injured, you go to the doctor. The doctor makes a diagnosis and prescribes treatment and the majority of the time, you recover.

Chronic illnesses like lupus don't work that way. Symptoms come and go for a long time. There is no definitive test to diagnose the disease. By the time you get to the doctor, the symptoms may abate. In chronic illness, you go to the doctor, it may take some time the doctor to make a diagnosis, the doctor prescribes treatment but to some degree you are still sick.

You feel alone. Happy, healthy people are all around you but you have a life sentence called lupus. The truth is that you are not alone. Roughly 1 in 3 Americans have a chronic illness. Most of them, like you, feel like they are alone. But there is hope. With education, information, and the right tools, you can learn to live well with lupus.

Lupus is an autoimmune disease. The causes of autoimmune diseases are not well understood. We all want to know why we developed lupus. The most important question is not "Why" it is "What's next?" and "What can I do?" You can't change what happened but you can choose your reaction to it.

Medications Used in the Treatment of Lupus

The Food and Drug Administration (FDA) has approved four medications specifically for the treatment and management of lupus: aspirin, steroids, hydroxychloroquine (Plaquenil) and belimumab (Benlysta). Other classes of medications are also used in the treatment of lupus. The medications and how they work are beyond the scope of this booklet.

Doctors often prescribe medications other than these four. Prescriptions are considered "off label" if the medication is not one of the four listed above. Methotrexate, rituximab (Rituxan) and azathioprine (Imuran) and mycophenolate mofetil (Cellcept) are examples. This does not mean the medications are harmful or that your doctor is experimenting on you. These medications have been used for other conditions for a long time and have been shown to help in the management of lupus. They have passed FDA approval for other diseases, but have not passed the hurdles for lupus at this time.

Most of us are used to medications working quickly. A pain killer relieves a headache or muscle pain. Antibiotics knock out an infection in 10 days. Medications used to treat lupus may take months to make a significant difference.

Keep taking your medications regardless of how you feel on any given day. If you have doubts about the effectiveness of your medication, talk to your doctor. Just as it may take months for a lupus medication to reach full effectiveness, it may also take months before the benefits wear off. Always talk to your doctor.

Medication

Risk versus Benefit: Allergy versus Side Effect

No medication is without some level of risk. When considering any medication, one must weigh the risks and the benefits. In cases of chronic illnesses like lupus, we are likely to be on medications for life. It is our responsibility to learn all we can and to weigh the risks and benefits of each medication. Your rheumatologist is your best ally in this process. Communicate! Ask questions!

All medications have side effects. Some people are allergic to certain medications. It is important to understand the difference between side effects and allergies. Side effects include things like nausea, diarrhea, dizziness, fatigue, etc. Side effects are annoying but not life threatening nor are they allergies. If you are having side effects, make sure you are taking the medication according to directions for example with food, milk, or a full glass of water. Some medications need to be taken on an empty stomach. Ask your doctor how to minimize side effects.

Read the medication insert and warnings. Allergies to medications may cause severe reactions. If you develop a mild allergic rash, call your doctor. For a more severe reaction, especially swelling of the lips, throat or tongue, call 911 or go directly to the emergency room. Bring your medication with you to the hospital. Knowing the difference between side effects and allergies is a critical part of managing your lupus well.

Remember that some supplements have a negative impact on the effectiveness of your medication, so talk to your doctor or ask your pharmacist! Each medication is different.

Lupus and Diet

Good nutrition is an important part of living well with lupus. However, there is no “lupus diet.” Chronic inflammation that accompanies lupus increases the risk of lupus patients developing cardiovascular disease. Inactivity as a result of fatigue or pain may lead to obesity and also may worsen inflammation. Some medications may result in elevated blood pressure. Obesity and elevated blood pressure compound the risk of heart attack and stroke.

Talk with your doctor about lupus and your individual needs. If you have high blood pressure, you might consider the Dietary Approach to Stop Hypertension (DASH). This program, developed by the National Heart, Lung and Blood Institute has been demonstrated to have a significant impact on high blood pressure. You can download the free booklet at:

www.nhlbi.nih.gov/health/public/heart/hbp/dash/index.htm. You can also order a free copy of NIH Publication No. 03-5232, *Your Guide to Lowering Your Blood Pressure with DASH* (2006). This informative booklet includes nutrition guidelines, recipes, and a week of sample menus.

Healthy eating means:

- Eating a variety of foods
- Eating regularly
- Eating a morning meal every day
- Eating the same amount at each meal

Healthy eating guidelines:

- Eat a variety of foods from all food groups
- Eat a minimum of five fruits or vegetables a day
- Choose foods lower in fat
- Watch your cholesterol level (fats that are solid at room temperature raise cholesterol)
- Choose carbohydrates from healthier sources like bread, grains, pasta, vegetables and fruits rather than sweets, pastries and candy
- Reduce the amount of salt or sodium in your diet

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Lupus and Exercise

Just like every other person, people with lupus need regular exercise. This doesn't mean you have to run a marathon, lift heavy weights, or spend half your day in the gym. Moderate exercise such as walking, swimming or bicycling for 30 to 45 minutes a day improves the quality of life for lupus patients and:

- Reduces stress
- Relieves depression
- Improves cardiovascular health
- Lubricates joints
- Helps maintain a healthy weight
- Improves quality of sleep

****Always talk with your doctors before starting or modifying your exercise plan.***

If you have not been exercising, you can start slowly. If your goal is to walk 30 minutes a day, you can start with just five minutes and gradually increase the length of time. You can also walk for five minutes six different times during a day. What matters is that you ultimately get in those 30 minutes, not that you do them all at once.

Lupus and Difficult Emotions

If you ask someone who they are, chances are they will identify themselves by what they do (such as their occupation or hobbies) or by whom they are in relation to others (spouse, parent, child, and friend). Lupus, like any chronic illness, changes our identity. We may have to make adjustments in our work and personal lives.

The result can be a flood of difficult emotions like anger, frustration, fear, despair, sadness, denial, depression and more. We might try to ignore or suppress these emotions only to find that they come roaring out at inappropriate times. We may have a hard time even identifying what we are feeling. All of this is quite normal. Adjusting to lupus is a process.

Difficult emotions need to be identified and expressed in healthy ways. Journaling is an excellent tool. You don't need anything fancy, just a notebook, a pen and some quiet time. The technique is simple; just write whatever pops into your mind. Don't judge the writing. Don't worry about grammar or spelling. Just write from your stream of consciousness and how you feel. Write for at least 20 minutes. The only rule is to keep the pen moving on the paper. Over time, as you express and release difficult emotions, they will lose their hold over you.

If you have difficulty finding private time at home, consider going to a park, coffee shop or library to write.

Lupus can be very isolating. You may feel like no one understands. You may feel very alone. In support groups, you will find people who understand what it is like to live with lupus. You will meet people who have managed to create a new normal for themselves and go on to have fulfilling lives. You will meet people who are newly diagnosed, feeling bewildered and don't know where to turn. You will meet veteran lupus patients who can help you find your way. Together we are all stronger.

If difficult emotions still persist, professional help might be in order. Talk to your rheumatologist. Depression can develop as part of trying to cope with your disease or it may have a biological origin. Psychiatrists can make this diagnosis and prescribe medication if appropriate. Medical psychologists and licensed social workers are excellent resources to help you deal with difficult emotions. Ask about their experience treating patients with chronic illnesses before making an appointment.

Lupus and Relationships

One of the most common complaints from lupus patients is, "They don't get it!" **They** refers to loved ones, friends, acquaintances, co-workers, etc. This complaint is frequently followed by repeated attempts to make "them" understand what it is like to live with lupus. They can empathize with you, but no amount of talking can make them have your experience.

If you are not vigilant, lupus can dominate your conversations and your relationships. You happen to have lupus. Lupus does not have you unless you allow it. Every casual inquiry about your health does not require a long litany of symptoms. Make a habit of observing your own conversations to see how much is about lupus.

Not everyone needs to know that you have lupus or how it affects you. Think carefully before you will disclose your condition. Don't let lupus define you!

Chronic illnesses like lupus put a strain on even the best relationships. Just as you are frustrated by the uninvited changes in your life, so are your partner and family. They want to help you feel better, but feel helpless to do so. Communication is critical.

Practice using "I" messages. Instead of saying, "You never help me out," say, "I feel frustrated that I can't keep up with the housework." "I" messages let the other person know how you feel without attacking them. Another way to use "I" messages is to say, "When this happens, I feel _____."

Say what you need instead of assuming that the other person knows. The other person might not know. It's easy to build up resentment when your needs are not being met.

On the other hand, your loved ones may jump in and do things you would rather do for yourself. It's OK to say, "Thanks for offering, I really appreciate that. I would like to do this myself. I promise to ask for your help when I need it."

Have an honest discussion about how each of you feels about lupus and the changes in your lives. Agree to make an extra effort to send "I" messages and to communicate honestly. If necessary, a mental health counselor can teach you.

Lupus and Stress

Stress is a major factor in causing lupus flares. But having lupus is in itself stressful. The unpredictable nature of lupus makes planning for the future difficult. Relationships are impacted. Frequent visits for laboratory tests and doctor appointments become part of our lives. Our ability to earn an income may be impacted while at the same time we are incurring increased medical expenses. It seems like a Catch-22.

There is hope. First, our bodies react to stress whether a threat is real or just perceived. What we think causes what we feel. What we feel causes a cascade of reactions in our bodies. If you are imagining a hospitalization, disability, or poverty your body reacts as if it is facing that situation in reality.

The first step is a reality check. Is this threat real and imminent? If so, then decide on a course of action and do it. Ask yourself what evidence you have to support your stressful thoughts. If you can't sort this out on your own, talk to a trusted loved one or friend. Support group members may also be able to help.

Cultivate mindfulness of your thoughts. We can't stop thinking. Minds think. That's what they do. But we can become aware of what we are thinking. We can pay attention to the endless self-talk and find out what's going on. Journaling, prayer and meditation are good ways to do this. (See tips for journaling under Difficult Emotions).

Full Catastrophe Living by Jon Kabat-Zinn and *The Mindfulness Based Stress Reduction Workbook* by Bob Stahl, et al. are excellent places to start.

Dr. Jon Kabat-Zinn developed the Mindfulness Based Stress Reduction (MBSR) program at the University of Massachusetts Medical Center. Since its inception, MBSR has evolved into a common form of complementary medicine addressing a variety of health problems. The National Institutes of Health's National Center for Complementary and Alternative Medicine has provided a number of grants to research the efficacy of the MBSR program in promoting healing. Completed studies have found that pain-related drug utilization was decreased, and activity levels and feelings of self-esteem increased. Find a psychologist trained in MBSR, online courses, and other resources at the website:

<http://www.mindfullivingprograms.com/whatMBSR.php>

Talking with Your Doctor

Your medical team is a critical component in managing lupus. Good doctor/patient communication is essential. Talk! The current medical system limits the time you may have with your doctors therefore you must make every minute count. Here are some tips:

Be honest. Your doctor can't help you if you don't tell the truth. Report your symptoms, whether or not you are taking your medication as prescribed and if you are taking supplements or over the counter medications.

Keep a symptom journal. Record the following issues and make a concise summary before your next medical appointment. Your doctor does not have time to weed through a long list.

What is the symptom?

When did it start?

How often do you experience this symptom?

How long does the symptom last?

To what degree does the symptom interfere with your activities of daily living?

What provides relief from the symptom?

What makes the symptoms worse?

Have you identified any trigger for the symptom?

Provide your doctor with a list of medications (both prescription and over the counter) including dosage amount and frequency. Include all vitamins, herbs and supplements.

Ask your questions at the beginning of the appointment. Near the end of the appointment, your doctor may consider the appointment over and be moving on mentally.

Have copies of your laboratory and test results delivered to *all* your medical providers. Do not assume that they will communicate with one another. You may also want to have copies of your medical records for your own personal file.

Be specific. If you have pain, describe it clearly. Is it dull, throbbing, sharp, constant, intermittent, cramping, triggered by activity, etc? Do the same for all symptoms.

Ask questions about your treatment options. The treatment of lupus is complicated. What works for one patient may not work for another.

Bring a written list of questions in priority order. You can assume that your medical provider will answer the first three or so questions. However, he or she will scan down the list of questions and may spot one that is important for your care.

If you are having difficulty reaching your doctor by phone or the office staff does not accurately relay your concerns, send a fax describing your concerns and asking the doctor to call.

Clinical Studies

Some clinical studies involve using human volunteers that in order to add to medical knowledge. There are two main types of clinical studies: clinical trials and observational studies.

In a clinical trial (also called an interventional study), participants receive specific interventions according to the research plan or protocol created by the investigators. Studies may test the effectiveness of new medications, may compare existing treatments to newer treatments, or study the long range effects of a medication. In an observational study, investigators assess health outcomes in groups of participants according to a protocol or research plan.

Learn more at: www.clinicaltrials.gov or www.lupustrials.org.

Evaluating Treatments

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Some lupus patients seek solutions to managing their lupus through supplements, complementary and alternative methods. While these may be helpful, some may actually make lupus worse or may counteract your medication. ALWAYS talk with your rheumatologist about these methods.

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Many people are quick to offer their opinions about how you should manage lupus. They will

tell you stories about relatives or people they know. They will suggest lifestyle changes, dietary changes and supplements. ALWAYS talk to your rheumatologist before you try something new. You could do more harm than good. Remember that “natural” is not always better. Hemlock and arsenic are “natural” but they can kill you!

Questions for evaluating treatment options:

Were the people who got better like you? Same symptoms, gender, age, ethnicity and organ involvement?

Is there anything else that could account for their improvement? Change in life circumstances? Change in stress level?

How did you hear about this? Friend or relative? Tabloid? Infomercial? Supplement sales person? Credible documented source? Internet?

Have the results been replicated?

Are you afraid to discuss this with your doctor? Why?

Does the treatment require you to give up certain foods?

Can you afford the expense financially and emotionally?

Note: The internet can be a great source of information and misinformation as well. Sites with addresses ending in .edu, .gov and .org are generally trustworthy. Many .com sites are also reliable but some exist for the purpose of getting you to buy their products.

Things to Avoid

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If you have lupus or a condition that predisposes you to lupus, such as undifferentiated connective tissue disease, there are certain foods and medications that you should avoid. The substances listed below have shown to induce lupus signs and flares and should be avoided by people with lupus or autoimmune diseases suggesting “pre-lupus.”

Sunlight

People with lupus should avoid the sun, since sunlight can cause rashes and flares. Some people are more sensitive to sunlight than others, but all people with lupus are advised to be cautious when they are outside. Carry a sunscreen with an SPF of at least 70 and be sure that your sunscreen contains Helioplex, an ingredient that blocks UV-A and UV-B rays, both of which are harmful to people with lupus. Apply sunscreen to all areas of the body, even those covered by your clothes, since most normal clothing items only protect your skin to the level of SPF 5.

Bactrim and Septra (sulfamethoxazole and trimethoprim)

Bactrim and Septra are antibiotics that contain sulfamethoxazole and trimethoprim. They are grouped as “sulfa” antibiotics because they contain a substance called sulfonamide. Bactrim

and Septra are often prescribed for bacterial infections, especially urinary tract infections. They are also sometimes given prophylactically (i.e., to prevent infection), especially in people taking immunosuppressive medications. However, caution is advised because these antibiotics may cause an increase in sun sensitivity and sometimes may cause lupus flares. If possible, alternative antibiotics should be used. But as always, risk needs to be weight against benefits.

Estrogen.

This is controversial. The SELENA trial shows no increased risk of “major flare” but slightly increased risk of “minor flare.” Use with caution.

Interferon alpha

This is used to treat hepatitis C and some forms of cancer. There is some evidence that it may trigger or worsen lupus. Use with caution.

In fact, an excellent website about what to avoid is: <http://www.hopkinslupus.org/lupus-info/lifestyle-additional-information/avoid/>

Things that May Be Beneficial

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Omega 3 fatty acids may reduce inflammation.

Vitamin D deficiency is common in lupus patients because they avoid the sun. Have your vitamin D level checked and take supplementation if it is low. Consult with your doctor.

Calcium helps protect against osteoporosis especially if you are taking steroids. It is important to get enough calcium and vitamin D and to treat other coexisting conditions such as high cholesterol.

Statins may be in order if your fasting lipid levels are high. Accelerated atherosclerosis is a problem in lupus patients.

Resources

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Some lupus patients can continue to work. Some lupus patients have to cut back on hours. Some lupus patients end up on disability. Our ability to work may change with the course of the disease. Regardless, lupus can be expensive to manage. The private and government assistance maze is challenging to navigate. Although information and programs do change, the following resources are a starting point for finding the help you may need.

Many applications for assistance are available on line. If you do not have a computer, internet access, or a smart phone please go to your local public library. You can go online at no charge and the reference librarians will be happy to help you if you are not internet savvy.

Find a Rheumatologist

Rheumatologists are the physicians who receive training in the diagnosis and treatment of lupus. You will need a rheumatologist and possibly some other specialists depending on how lupus affects you as an individual. Your rheumatologist should be able to guide you in finding the necessary additional specialists. You can find a rheumatologist at:

www.rheumatology.org.

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Partnership for Prescription Assistance is a resource to help patients pay for medications. Over 2,500 medications and 475 patient assistance programs are provided.

www.pparx.org (888) 477-2669

Needy Meds is an information source listing the manufacturers of many medications. Contact information is provided for patient assistance programs for each.

www.needymeds.org

Florida Discount Drug Card

The Florida Discount Drug Card is available to all Florida residents without restriction and is accepted at over 60,000 pharmacies nationwide. Florida residents who qualify based on age or income status are eligible to receive additional savings.

www.floridadiscountdrugcard.com (866) 341-8894 TTY (866) 763-9630

Co-Pay Relief

PAF Co-Pay Relief provides direct financial assistance to qualified patients, assisting them with prescription drug co-payments their insurance requires relative to their diagnosis.

www.copays.org (866) 512-3861

Healthwell Foundation

When health insurance is not enough, HealthWell fills the gap. We assist patients living with chronic and life-altering illnesses in paying their share of prescription drug copayments, deductibles, and health insurance premiums.

www.healthwellfoundation.org (800) 675-8416

Quest Diagnostics Patient Assistance Program

Quest may allow you to make payments and in some cases, may offer income based tiered discounts for your laboratory tests.

<http://www.questdiagnostics.com/home/about/corporate-citizenship/community-giving/assistance.html>

ACCESS Florida is your one stop portal for seeking assistance from the Florida Department of Children and Families. The Food Assistance Program helps individuals and families purchase nutritional foods needed to maintain and promote good health. The Temporary Cash Assistance program provides financial assistance to pregnant women in their third trimester and families with dependent children to assist in the payment of rent, utilities and other household expenses. The Medicaid Program provides medical assistance to individuals and families to cover or assist in the cost of services that are medically necessary.

<http://www.myflorida.com/accessflorida> (866) 762-2237 TTY (800) 955-8771.

Free or Reduced Health Care centers can be located through

United Way Resource Line

Call 211 from a phone that has the same area code as where you live. You will be connected to a resource operator who may be able to refer you to local community resources.

Free Clinics

Some areas of the state have free or low cost non-profit clinics. Call 211 or do an internet search for "free clinics (your county)".

Indigent Health Care

Many counties in Florida have indigent health care programs. Call your county information line and ask for Social Services.

Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI)

Social Security Disability Insurance pays benefits to you and certain members of your family if you are "insured," meaning that you worked long enough and paid Social Security taxes. You will not be eligible for Medicare until two years from the date you applied for SSDI and until after you have received a favorable decision, even if that is more than two years from your application date.

Supplemental Security Income pays benefits based on financial need. You may qualify for Medicaid. When you speak to a counselor ask about "medically needy" and "share of cost."

Although autoimmune diseases like lupus are found in Social Security's list of impairments, not

all lupus patients will qualify because the complexity of the disease varies widely from patient to patient. Some attorney's will give you a free evaluation before you begin the process. You are encouraged to do so.

Housing

The Department of Housing and Urban Development has several programs available to help with rent and housing. You can find current information and links to local resources here http://portal.hud.gov/hudportal/HUD?src=/topics/rental_assistance Learn about specific options in Florida here <http://portal.hud.gov/hudportal/HUD?src=/states/florida>

Feeding America

The mission of Feeding America is to feed America's hungry through a network of food banks and engage our country in a fight to end hunger. A local food bank search tool is available at www.feedingamerica.org The site also has links to public assistance programs.

St. Vincent de Paul Society

Many Catholic churches have a St. Vincent de Paul Society that provides small amounts of material assistance in emergencies. You do not have to be Catholic to receive help, but you must live within the church's geographical boundaries. Call the nearest Catholic church to find out.

Help Making Insurance Decisions

SHINE (Serving Health Insurance Needs of Elders) is a free program offered by the Florida Department of Elder Affairs and your local Area Agency on Aging. Specially trained volunteers can assist you with your Medicare, Medicaid, and health insurance questions by providing one-on-one counseling and information. SHINE services are free, unbiased, and confidential. They are also available to help people on disability. (800) 963-5337
<http://www.floridashine.org/>

Find Health Insurance

The Affordable Care Act prohibits insurance companies from discrimination, denying coverage to and from charging exorbitant rates for people with pre-existing conditions. If you at a low income level, your insurance may be subsidized by the government. Learn more at: (800) 318-2596

www.healthcare.gov

Florida Kid-Care

Through Florida KidCare, the state of Florida offers health insurance for children from birth through age 18, even if one or both parents are working. When you apply for the insurance,

Florida KidCare will check which part your child may qualify for based on age and family income. (888) 540-5437

TTY (877) 316-8748. Learn more at:

<http://www.floridahealth.gov/AlternateSites/KidCare/>

Dental Care

If you cannot afford dental care, you may be able to get help through a local clinic (see Free Clinics) or from a dental hygienist program at your local adult education center, community college, university, or private college. Qualified dentists work in these facilities.

Support Groups and Educational Seminars

The Lupus Foundation of Florida offers local support groups with trained facilitators and periodic educational seminars around the state. We send frequent electronic newsletters with the latest news in lupus research and tips for living well with lupus. Check website for the latest events and to subscribe to the newsletter at:

www.lupusflorida.org

Suggested Reading

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