

lupus **FACT SHEET**

Lupus Canada

Talking about lupus

 "I have lupus."

If you have systemic lupus erythematosus (SLE or lupus), these may be the most difficult words you ever speak. How – or indeed, whether – you tell people that you have lupus is a personal decision. But it is important to remember that dealing with a chronic illness requires support, and people cannot offer their help if you don't tell them what you need.

Reaching out

All too often, people with chronic diseases such as lupus are hesitant about telling others about their condition. Particularly if you are young, it may be difficult to reveal what you perceive to be a weakness or something that sets you apart from your friends and colleagues. You may fear their reaction: will they reject you? Pity you? Dismiss your symptoms? Treat you differently than before? Even with friends and family with whom you have shared your diagnosis, you may hesitate to talk about how you feel (emotionally and physically) for fear of becoming burdensome.

However, failing to communicate with the important people in your life isn't the way to deal with these fears, as isolation often leads to depression, stress and ultimately poorer lupus management. Open communication, on the other hand, gives others the opportunity to help support you through the challenges that lupus presents. For example, one American study on the impact of lupus on married couples found that women with lupus who shared their problems and feelings with their husbands during a

lupus flare fared better than other women with lupus who experienced less emotional intimacy with their spouses. The researchers concluded that sharing their problems and feelings gave wives the opportunity to have their feelings validated and to receive reassurance from their husbands that they were accepted and loved unconditionally even though they were ill.

You don't have to share your diagnosis or feelings with everyone in your life, of course. Rather, create a support network of people you trust, such as close friends and family members.

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Joining a support group can also be helpful. Lupus is misunderstood by many people, so it is particularly important to have your experiences validated by others who are going through the same thing. Visit Lupus Canada to find a lupus organization in your area.

How to tell

Plan ahead: The first few times that you tell people that you have lupus, you may want to plan ahead and think about what you want to say. Different people need to know different things about the disease. Your employer, for example, will want to know how lupus will affect your ability to work, while your parents may need to hear reassurances that they didn't "cause" your disease through something they did in your childhood.

Anticipate questions: Try to anticipate the types of questions that people might ask and prepare to deal with them. Think of a response for questions that you don't want to answer. For example, if a co-worker asks, "Does



lupus mean you can't have children?" you could answer, "I'm not ready to discuss such a personal issue."

Take charge: Don't wait for a lupus flare to tell others about your disease. You will likely be too tired or in too much pain to express yourself clearly. Take charge of the situation by choosing when to initiate the discussion. Pick a time when you are at your best and your audience can give you their undivided attention.

Express your needs: Some people will respond to your news with a sincere and immediate offer to help in whatever way you need. Others may worry that you will expect them to help more than they want to. Regardless of your audience, be sure to explain clearly what you need from them, even if it's just their understanding.

Educate: Lupus is poorly understood by the general population, so there is a good chance that people will have no idea what you're talking about or will react based on misinformation about the disease. And because there are often no outward signs of lupus (or the steroids you take give you a "healthy, rosy glow"), there may be some disbelief or skepticism about your symptoms. Informing people about the facts of lupus will help them understand how it affects you and what you are capable of. Offer them brochures or fact sheets about the disease or direct them to reliable lupus websites.

Listen and understand: Don't be so focussed on what you have to say that you forget to listen to the other person and empathize with them – just as you want them to do for you. They will have questions and concerns, just as you did when you first heard your diagnosis. People's reactions to your news will depend on your relationship with them. The closer you are, the more emotional they may be. Your parents may feel guilty, your husband angry, your best friend frightened. Although these emotions may seem like an extra burden to you, recognize that they come from concern for you. The greatest support you, your friends and your family can offer is to listen to each other.

Get help: In some situations, it is helpful to involve a third party. At work, you may want to ask someone from Human Resources or your Employee Assistance Program to help you talk to your boss. At home, a social worker can help your family cope with and understand your disease.

At work*

The fact that you have lupus is your business, and you have the right to keep that information private, even at work. During a job interview, it is illegal for an employer to ask specific questions about your medical history. They can only ask questions directly related to the job you are applying for. For example: "Are there any circumstances in your life that might prevent you from fulfilling the requirements of this job?" or "Do you foresee a problem with attendance?" If you are reasonably

INFORMATION FOR FRIENDS AND FAMILY — HOW YOU CAN HELP

When a loved one tells you that they have a serious, chronic illness, it is often difficult to know what to say and how to help. Some people become distant for fear of saying or doing the wrong thing. Here are some suggestions to help you help someone with lupus:

1. Don't try to boost their spirits if they aren't feeling receptive to it.
 2. Don't try to divert them. If the topic of their health is on their mind, then it is important to talk about. Allow the person the opportunity to talk about their illness and their feelings.
 3. Try not to be afraid to talk about the illness.
 4. Don't be afraid of causing tears. You shouldn't feel like you're walking on eggshells around the person.
 6. Reassure – don't argue.
 7. Communicate – don't isolate.
 8. Perform some concrete act. You might offer to help with a chore such as grocery shopping or cooking. You might ask "how can I help you?"
 9. Swing into action.
 10. Get them out of themselves.
- Adapted from "A Treasury of Comfort" by Sidney Greenberg.

sure that your lupus won't interfere with your ability to show up and do your job, then there may be no need to mention your disease. It is your choice as to whether or not you disclose your health information. The exception is if you are applying for a "safety-sensitive" position (such as an airline pilot or police officer), in which case you must disclose any medical condition that could jeopardize the safety of your co-workers or clients. However, some people choose to tell their employer about having lupus – this could help you to determine how supportive your employer and work environment may be to people with health conditions. But be aware that talking about your health during the interview process could have an impact on an employer's decision to offer you a job.

Once hired, you are not required to tell anyone about your condition except if your employer has an absenteeism policy that requires you to provide a medical certificate if you have been absent for a prolonged period of time. You may also have to disclose your medical condition to your employer if you are claiming employee benefits and your company requires claims to be submitted to them directly.

Although infrequent, some employers require all staff to have a medical examination for health-benefit purposes. If the exam reveals your lupus (or any other medical condition), this information is not to be shared with your employer. If your condition requires accommodations on the employer's part (for example, scheduling periodic rest breaks), the employer has an obligation to try and meet your needs up to the point of undue hardship. On the other hand, if you can't meet the job requirements because of your lupus, your employer may have to terminate your employment. You can check with provincial employment standards or an employment lawyer to ensure your rights are being respected.

If your lupus flares after you have been hired, your job is protected. It is a violation of human rights legislation to

fire a person after discovering they have a chronic or progressive disease.

It may make sense for you to tell your employer and co-workers about your lupus at some point. If they are aware that you have health issues, being secretive may create unnecessary anxiety for you and also among your co-workers. Provide brochures or other information about lupus, as understanding the illness may make them more comfortable. Explain how lupus affects you in terms of doing your job. If you require accommodation, tell your employer what you will need to continue to work.

At School

Colleges and universities usually have a department that provides assistance to students with disabilities or health conditions. Assistance varies by school, so if you're in the process of applying for post-secondary education, find out what services are offered. If you are a new student, make contact with the staff early on, even if your lupus is stable at the moment. It's better to introduce yourself now than when you're stuck in the hospital and about to miss an exam.

These departments can help with many problems. For example, if your joints are too swollen to write or you have trouble concentrating in class, they may arrange for a note taker to help you. They may also arrange extra time for you to write exams, or ask the professor to provide an exam in an alternate format (for example, you could give verbal replies rather than written ones). The staff can also look into physical accommodations, such as accessible dormitories and single dorm rooms that would allow you to get more rest than if you had a roommate. They can also help you with dietary concerns (for example, if your dorm's meal plan isn't suitable).

You are not obligated to tell your professors that you have a chronic illness, but again, it may be better to discuss this

with your professors early on, even if you're feeling well, in case you have a flare during the school term and require extra time to hand in an assignment or need to make up a missed test or exam (they may request a doctor's note).

Insurance*

Unfortunately, human rights regulations do not apply to health insurance policies the same way they do to employment. Health insurance companies have the right to question you about your medical history and to refuse coverage based on that history. Even if the health insurance company doesn't ask you directly about lupus, you must disclose all information about your health. If you don't, the company can void your policy. Still, health insurance companies have different policies, so be sure to shop around even if you are refused coverage the first few times. The same principles apply to cancellation and medical coverage insurance when you are planning a trip.

**Adapted from "The disclosure dilemma. Should I tell? Must I tell?", Diabetes Dialogue, Spring 2003.*

Safety first

Even if you choose not to disclose your lupus to people around you, wear a MedicAlert bracelet or medallion and carry the MedicAlert card in your wallet, especially when travelling. These are recognized around the world and could save your life in a situation in which you cannot speak for yourself. Ask your pharmacist for details.



FOR MORE INFORMATION

- Lupus Canada: www.lupuscanada.org. This site includes electronic versions of the *Living Well with Lupus* fact sheets.
- *Lupus: The Disease with a Thousand Faces*, edited by Dr. Sasha Bernatsky and Dr. Jean-Luc Senécal, Key Porter Books (2004) ISBN 1-55263-603-8. Contact Lupus Canada to order this book.
- Living Well with lupus – personal stories from people who are living with lupus can be found on the Lupus Canada website
- The Arthritis Foundation: www.arthritis.ca
- Lupus Discussion Board:
<http://www.arthritis.ca/open%20forum/boards/lupus/default.asp?s=1>

Disclaimer

Systemic lupus erythematosus is an autoimmune disease that affects thousands of Canadians, mostly women in their childbearing years. Symptoms vary greatly from person to person and treatment is highly individualized. Patients are urged to contact their physician or healthcare professional with any questions or concerns they might have.

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