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Other Resources:

- Visit the Lupus Canada website for more lupus information, lupus fact sheets and local resources – www.lupuscanada.org
- The Arthritis Society – www.arthritis.ca
- Lupus Foundation of America – www.lupus.org

lupus  **FACT SHEET**

MEN AND LUPUS

Systemic lupus erythematosus (SLE), or lupus, is far more common in women (affecting approximately nine women for every man) but men do get lupus. Most women are diagnosed with lupus during childbearing years, but for men the onset of symptoms may occur at any age including childhood. During puberty, about 25% of people diagnosed with lupus are young men, and in later years, about 20%-40% of the newly diagnosed lupus patients are men. There are an estimated number of about 5,000 men living with lupus in Canada.

Systemic lupus in men can present similarly to lupus in women. This can include skin rashes, pleurisy, fatigue, neurological illnesses such as peripheral neuropathy (inflammation of the nerves in the arms and legs), joint pain, kidney disease, Raynaud's phenomenon and vasculitis (inflammation of the blood vessels). Discoid lupus erythematosus (DLE), which is non-systemic, involves localized skin rashes (coin-shaped scaly lesions generally found on the scalp, face, cheeks and nose). DLE is usually painless, but for some may be quite painful. Patients with DLE may be very photosensitive, and need to limit their sun exposure to reduce lesions and possible scarring.

Drug-induced lupus (DILE)

Drug-induced lupus is the result of certain medications that cause lupus symptoms such as joint pain, muscle pain, fever, arthritis and inflammation of the heart and lung. These symptoms can be mild, moderate, or severe.

More men develop DILE than women, probably because more men seem to be prescribed medications that produce DILE. The most common drugs that result in drug-induced lupus include medications for heart disease, and high blood pressure.

After discontinuing the medication, lupus symptoms gradually disappear, but this may take many days, months or longer to disappear.

Diagnosing men with lupus

In order to diagnose lupus there needs to be comprehensive history and physical examination and investigations, such as blood tests. The American College of Rheumatology for research purposes had identified 11 diagnostic criteria some of which pertain to findings in the skin, blood, joints and organs. The presence of at least four of the criteria indicates a diagnosis of SLE by this standard. However, it is possible for a rheumatologist to confirm an SLE diagnosis in some patients, even if the patient does not meet ACR research criteria. Common manifestations include rash, oral ulcers, and inflammatory arthritis. There are other organs that can be involved including the kidneys, lungs and brain.

Hormones and SLE

It has long been thought that hormones may play a role in the prevalence of lupus in both men and women. Studies have found that:

- Young men with lupus have been found to have normal levels of Testosterone (a male hormone), however there is some evidence that lower levels of testosterone in both young and older men may predispose these men to autoimmune-like diseases
- There is no increase of estrogen (a female hormone) in men with lupus

More research is being done on the hormone androgen. It has been found that women with lupus metabolize androgen at a faster rate than women without lupus, and thus have a lower amount of this hormone in their body. This is of interest, as androgens have been shown to have some immunosuppressive properties. As well, researchers want to find out if androgens explain the lower number of men having lupus compared to women.

Why do some men get lupus?

It is unclear why men get lupus, but it appears that in some animal studies on lupus, both men and women who have lower active testosterone levels at the cellular level may have an increased risk of autoimmunity or a lupus flare. Lupus may be caused by a combination of genetic predisposition with certain variables, such as a viral illness or stress or other factors that might stimulate your immune system to trigger an autoimmune reaction.

Will my children be at risk of lupus if I am a male with lupus?

Lupus rarely runs in families. Lupus occurs in about 1 in 2,000 people in the general population.

In families of lupus patients there is an increased risk of lupus, rheumatoid arthritis, scleroderma, juvenile arthritis and polymyositis. However, this risk might only be 1 to 5% which is higher than the risk for the general population, but not as strong a risk as that seen with genetic illnesses, which often have a 25% to 50% risk. Therefore, men with lupus who would like to have children should not let lupus change their minds. Speak to your physician if you have other concerns regarding your health or how

medications you may be taking could have an impact on your ability to be a parent.

Are there special treatments that men with lupus should have?

Men and women with lupus are treated in similar ways. Your physician will treat the signs and symptoms and monitor organ involvement and the severity of the lupus. Treatments may include anti-inflammatory medications for the joints and anti-malarial drugs for skin and joints. Immunosuppressive medications are usually reserved for significant internal organ involvement or sometimes in severe joint involvement.

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Working together to conquer lupus

Staying healthy

It is important to learn to live well with lupus. This includes monitoring your health and developing preventative coping strategies. Here are some tips to help you stay well:

- Avoid or limit sun exposure
- Eat well. Choose a balanced diet, select natural foods, eat complex carbohydrates and fibre, and monitor your calorie intake
- Keep well hydrated with water. Drink at least two litres (eight glasses) per day. However, some people, for medical reasons such as kidney or heart failure, should restrict this intake; discuss with your doctor in these cases
- Stay as physically active as possible. Start with gentle exercises and build up to at least 30 minutes per day at least 4 days per week
- Consult with your physician, who is a key ally to maintaining your health and controlling lupus flares. It is important to keep your physician informed about your general health too
- Try to manage the symptoms that you are experiencing. These could include rashes, unexpected hair loss and weight gain or loss. You might be experiencing lowered self-esteem, or perhaps you feel pressured to provide for your family, maintain an active sex life or keep working. Perhaps you resent not being able to participate in enjoyable activities. It is important to find opportunities to discuss your feelings and concerns about your health and living with lupus and seek the support of others, including family, friends and professionals.

Consult with your physician, who is a key ally to maintaining your health and controlling lupus flares

- Stop smoking, as it could aggravate your symptoms, decrease the effectiveness of some medications and increase the risk of cardiovascular disease

- Manage your pain and fatigue. Create times to rest and nap to build up your strength. Try exploring a relaxing hobby or activity that isn't too demanding for your body. Some people find gentle exercises, massages, activity in a warm pool as natural ways to reduce pain. Remember to give into your body – fatigue is the body's way of saying it needs time to take it easy and catch up. And allow times to relax your mind through reading, relaxation and visualization programs, focusing on your breathing and other stress-reduction strategies.

Systemic Lupus Erythematosus is an autoimmune disease that affects thousands of Canadians, mostly women in their child-bearing years. Symptoms vary greatly from patient to patient and treatment is highly individualized. Patients are urged to contact their physician or health professional with any questions or concerns they might have. Opinions expressed on these fact sheets do not reflect those of Lupus Canada. To learn more about lupus, read the other fact sheets produced by Lupus Canada.

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