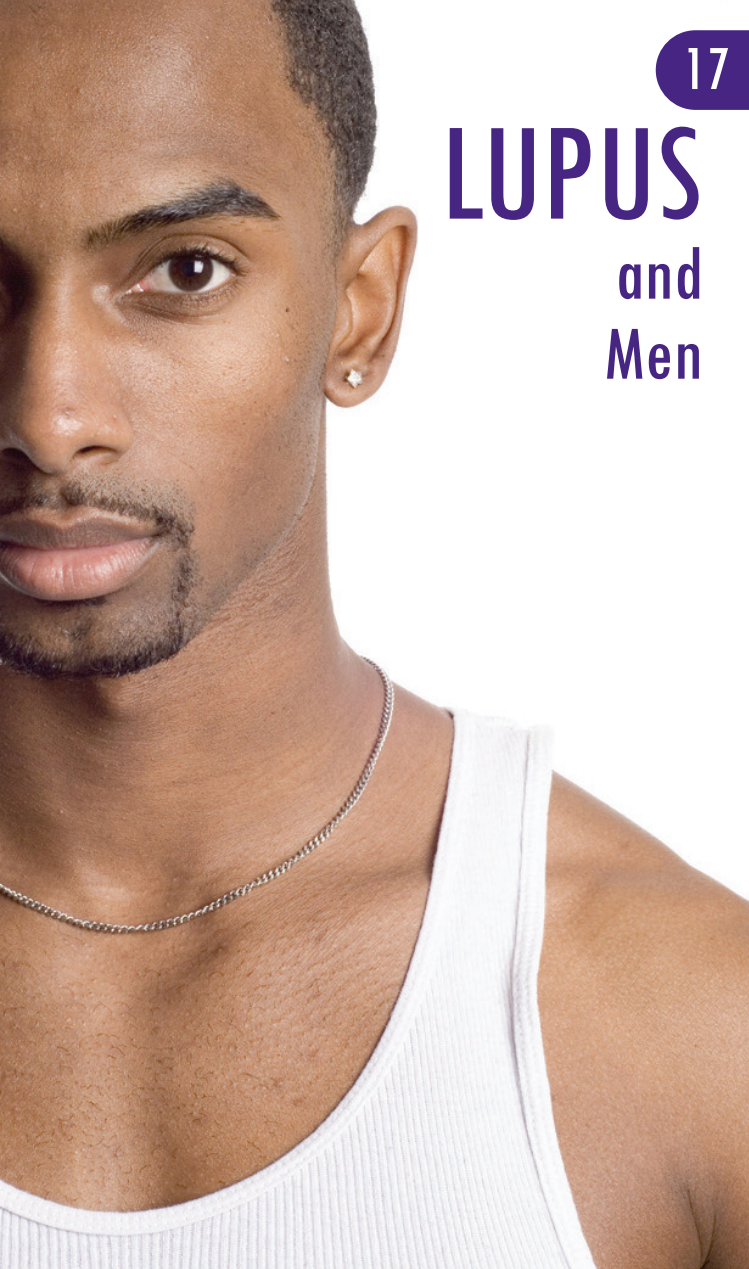


LUPUS

and
Men

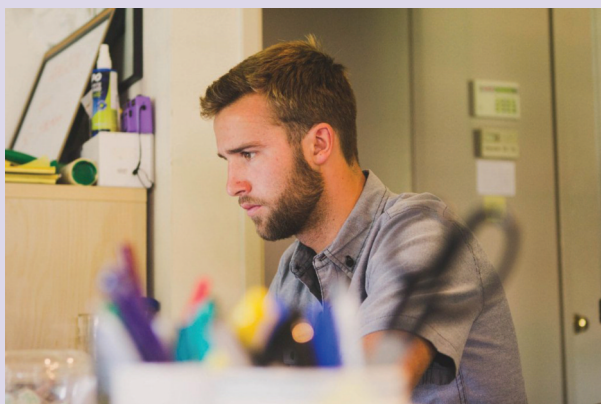


LUPUS and Men

Systemic lupus erythematosus (SLE or lupus for short) is about ten times more common in women than it is in men. There are very few diseases in which the difference between the two sexes is so great. From the point of view of men with lupus, this means that much of the clinical and research information available about lupus may seem to relate mainly to women and they wonder how much applies to them. This raises some questions, which will be addressed in this factsheet.

Why is lupus so much more common in women than in men?

No-one knows exactly why this is. Men and women have different sex chromosomes and so differences in genes on these chromosomes may be important. Men and women also have different sex hormones, and this probably plays a role in the development of lupus. The evidence suggests that hormones can exert an important influence on the immune system and, in particular, that the female hormone oestrogen can affect the development of lupus.



Some studies have suggested that levels of male hormones-called androgens - are reduced in men with lupus but these observations have not been supported in the majority of studies. However, there is a difference in the way that the androgens are metabolised (processed) between the genders. There is a suggestion that women with lupus metabolise androgens at a faster rate than those without

lupus and, consequently, have lower levels of certain androgens. Androgens have been shown to have some immunosuppressive properties. However, trials in which women with lupus were treated with androgens did not show any definite benefit. There is no evidence that any form of hormonal treatment would help men with lupus.



Is lupus in men different from lupus in women?

Comparing the clinical features of lupus in men and women is difficult because most clinics have very few male lupus patients to study. However, over the last 30 years there have been a number of reports from different countries that have made this comparison between genders. Different results were reported by different groups but overall there is no strong evidence that lupus is either more severe or less severe in men compared to women.

The most consistent findings between the different studies were that men with lupus were less likely to suffer from Raynaud's phenomenon (i.e. fingers changing colour from white to blue to red in cold weather) or photosensitivity (i.e. lupus rash worsened by sunlight) than women. Alopecia (baldness) is more likely to be noticed as abnormal by women than men. A number of studies showed that men were more likely to develop kidney disease than women. Overall, there is nothing to suggest that men with lupus should be looking out for different symptoms compared to women with lupus. For example, patients of both genders should be monitored for signs of developing kidney disease, such as checking urine samples for protein at clinic visits.

It is increasingly recognised that patients with lupus have a higher risk of developing heart attacks and strokes compared to people of the same age and sex without lupus. Overall men have a greater risk of developing heart attacks and strokes compared to women. This means that men with lupus should avoid other things that increase this risk, notably smoking.



Are treatments and side-effects of treatment different in men with lupus than in women?

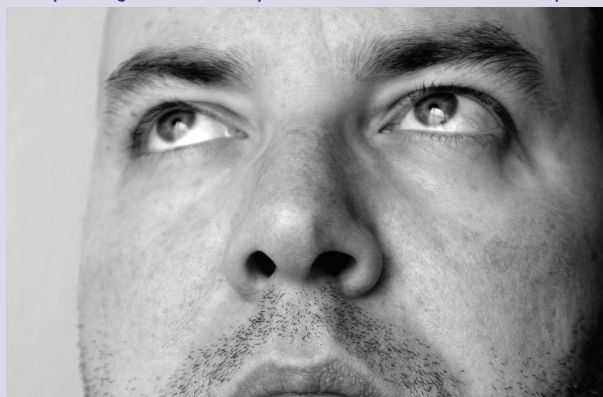
The short answer to this question is no. The same drugs can be used in patients of either gender. Some drugs that are avoided in women who want to have children can be used in men. Mycophenolate is an example of such a drug. The main drug

used in lupus, for which there are concerns about effects on male fertility is cyclophosphamide. Men who are treated with this drug should discuss the possible effects on fertility with their doctor.



Lifestyle considerations

Men may react differently from women when the diagnosis of lupus is given. This may be because of the misconception



that lupus is a woman's disease giving rise to the idea that a man with lupus is less masculine than his colleagues without lupus. This is not true. As discussed above, most men with lupus, as far as sex hormones and sexual function are concerned, are no different from men without lupus. Men with lupus are usually sexually active, potent and have normal reproductive histories. There may be some interruption in this when the disease is very active or with the use of certain drugs, especially cyclophosphamide which can affect fertility (see "Lupus and Medication" factsheet). Many of the day to day stresses in life are equal emotionally for men and women with lupus. However, in some ways it may be more difficult for men to cope with having lupus because of the pressures created by what they think their family, friends and society expect of them. They may not be able to work, or follow hobbies, in the environment previously expected of them (eg in the cold due to Raynaud's phenomenon). There may be difficulties in performing activities that require physical strength or prolonged periods of physical labour and a change of role in the work place may be desirable but not always available. Although attitudes are changing, many men feel that they should fill the role of provider for the family. If a man with lupus has to stop working or change job this may

result in significant financial and emotional stress. However, this is by no means necessary in most men (or women) with lupus. With earlier diagnosis and better treatment, many patients can remain in work, although some will have to change job, modify duties, or reduce the hours compared with their colleagues. Combined advice from an occupational health physician at the workplace and the lupus physician may be required to establish what type and level of work is appropriate for an individual with lupus. Similarly, lupus patients may have to discuss with their family and consultant how to adjust their leisure activities and hobbies, as it is essential that they get enough rest and remain as physically and emotionally fit as possible. This advice applies equally to men and women.

Another aspect of the disease that men (and women) have to cope with is the change in physical appearance. Rashes, unexpected hair loss and weight loss or gain may not be appreciated as being as important to men as to women. However, these symptoms may result in further loss of self-esteem and the feeling of loss of masculinity, particularly in young men. Patients with lupus may feel depressed or anxious due to having a chronic disease or because of having to take medications long-term. These emotions and worries should be recognised and patients may benefit from counselling or being able to talk to other patients about them. See Factsheet Lupus and Depression available from LUPUS UK.

Often men find it difficult to talk about health matters or seek support from self-help groups. They can appreciate one to one informal chats more than taking part in predominantly female meetings.



Conclusion

Men, like women, will need to discuss their lupus disease and its likely effects on their health and lifestyle with their consultant. Every case is different, but certain generalisations will be possible based on the clinical picture (what parts of the body are affected) and the results of blood tests and other investigations. There is no definite evidence that the disease is more severe in men than women, or that men with lupus have more female hormones or less male hormones than those without lupus. Fertility is not usually affected but active disease and certain drugs may affect sexual function and this needs to be discussed openly by the patient and his physician.

The LUPUS UK Range of Factsheets

A range of factsheets are available as follows:

1. LUPUS Incidence within the Community
2. LUPUS A Guide for Patients
3. LUPUS The Symptoms and Diagnosis
4. LUPUS The Joints and Muscles
5. LUPUS The Skin and Hair
6. LUPUS Fatigue and your Lifestyle
7. LUPUS and Pregnancy
8. LUPUS and Blood Disorders
9. LUPUS and Medication
10. LUPUS and the Kidneys
11. LUPUS and Associated Conditions
12. LUPUS and the Brain
13. LUPUS The Heart and Lungs
14. LUPUS The Mouth, Nose and Eyes
15. LUPUS and Light Sensitivity
16. LUPUS and the Feet
17. LUPUS and Men
18. LUPUS and Mixed Connective Tissue Disease

LUPUS UK is the registered national charity caring for people with lupus and has over 5,500 members who are supported by the Regional Groups.

LUPUS UK acknowledges with gratitude the assistance of Prof Anisur Rahman, Professor of Rheumatology and Consultant Rheumatologist, Centre for Rheumatology, Division of Medicine, University College London in the provision of clinical information towards the production of this factsheet.

LUPUS UK also thanks the Wooler Walkers (Northumberland) for their valued sponsorship towards the cost of producing the factsheets.

Please contact our National Office should you require further information about the sources used in the production of this factsheet or for further information about lupus. LUPUS UK will be pleased to provide a booklist and details of membership.

LUPUS UK is certified under the requirements of the Information Standard.



St James House, Eastern Road, Romford, Essex RM1 3NH

Tel: 01708 731251 www.lupusuk.org.uk

Reg. Charity nos. 1051610, SC039682