

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, they may result in further loss of self esteem and the feeling of loss of masculinity, particularly in young men. More serious problems such as disability due to stroke causing paralysis of one side of the body is even harder to cope with and may cause profound depression which needs active treatment as well as physical rehabilitation by physiotherapists.

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.

THE LUPUS UK RANGE OF FACT SHEETS

A range of fact sheets 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 presently incurable lupus and has over 6,000 members who are supported by the Regional Groups.

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Please contact our National Office should you require further information about lupus. LUPUS UK will be pleased to provide a booklist and details of membership.

LUPUS and Men



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.

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LUPUS and men

Although systemic lupus erythematosus (SLE or lupus for short) is about ten times more common in women than it is in men, it is important not to forget the men with lupus and the effects of the disease on their health and life. In particular, the development of a chronic disease may necessitate life style changes which can alter their traditional role within the family.

Hormonal influences on lupus

The role of sex hormones in lupus is suggested by observations showing that about ten times as many women as men have 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 there are differences in the way that sex hormones are chemically changed in lupus patients. Males and females with lupus have increased amounts of 16-hydroxylated oestrogens, and female, but not male, lupus patients have increased oestriol. The 16-hydroxylated compounds are the ones which can interact with cells of the immune system and which may be important in lupus. Levels of these compounds can be increased by taking the oral contraceptive pill containing oestrogen. These contraceptive pills have been reported to trigger the start of lupus or to cause it to have greater impact on some female patients.

Some studies have suggested that levels of testosterone, one of the male hormones or androgens, are reduced in males with lupus but these observations have not been supported in the majority of studies. However, there is a difference in the way that the male hormone androgen is metabolised (processed) between the sexes. 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. Recently, studies have been started in which androgens are being tested as a treatment for lupus in women, but the potential value of such treatment for males with normal androgen levels is unclear. For the few men with low androgen levels they may be of benefit, and would reduce the risks of osteoporosis, even if they are not effective at suppressing lupus disease.

Clinical disease in men

Although lupus is uncommon in males, it does not differ clinically in major ways from the presentation of lupus in females. Some have suggested that lupus is more severe in males but most studies have not found this to be so. The difference may be explained by a delay in diagnosing or treating lupus in males, as the disease is less often thought of in men, being more common in females, and because men may be more reluctant to seek medical advice than women.

The aspects of lupus which have been reported to be increased in males in some studies include skin rashes, pleurisy, neurological disease affecting the nerves in the arms and legs (peripheral neuropathy), kidney disease, vasculitis and Raynaud's phenomenon. Impotence has been reported in some patients with abnormal hormones, particularly low androgen levels. More men develop drug-induced lupus than women mainly because medications that produce drug induced lupus are more frequently used in men. These drugs include hydralazine and procainamide, and may reflect more heart disease in men than women. However, in recent studies it has been shown that it is women with lupus, particularly those in their forties, who are at increased risk of heart attack and stroke compared with women without lupus of the same age and whether men with lupus are at greater risk of these conditions than men without lupus of the same age is not yet clear.

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 males 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" fact sheet).

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 necessary but not available. Historically it has been the male who is the 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 is appropriate work 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.