

adequate pain relief without feeling drowsy. Some drugs eg beta blockers, can diminish sex drive. It may be possible, on advice from your doctor, to change the brand of drug being used to one which does not have this effect. If this is not possible you should explain to your partner that your medication is responsible for your lack of libido and that you are not just 'cooling off' your relationship! With Raynauds, the circulation of blood being restricted may also cause you to feel pain and uncomfortable during love making. Warm baths and a warm atmosphere can help.

Dryness — just as some people develop sore eyes and mouth you can also develop a sore and even sometimes ulcerated vagina. Ulcers should not necessarily inhibit lovemaking. Soreness and dryness may be overcome with longer foreplay to increase lubrication or by using lubricants such as KY jelly. If this soreness and dryness persist it may be necessary to seek medical advice. Don't be embarrassed, you will not be the first person to consult your doctor about this problem.



## Social life and friendships

Your friends will react to your condition in a similar way to your family and it is up to you to decide how much or how little you think they need to know. As for your social life, let your body lead you in this. Do as much as your body allows and continue to enjoy your life like many others with lupus do.



## Will lupus affect my finances?

If you find you are unable to work for long periods of time it may be there are benefits you can claim. A social worker should be able to help you with any enquires you have. You will usually need to give the name of someone who knows about you and your condition when completing forms. This is often your lupus specialist, nurse or GP. If you don't ask you won't know if you are entitled to financial help. The Citizens Advice Bureau can also be a source of useful advice.

Hopefully this fact sheet has helped answer some of the questions you have regarding changes to your lifestyle and how to cope with fatigue, but it is important to remember you never have to be on your own - there is always someone to listen to your fears and anxieties. Your family and friends, your lupus specialist or nurse and LUPUS UK and local lupus group contacts are just a few of the important people who will help you come to terms with your illness.

# 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 UK

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# LUPUS Fatigue and your Lifestyle



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# LUPUS

## Fatigue and your Lifestyle

### **What can I do to help with fatigue?**

Almost 90% of lupus patients experience fatigue, making it one of the most common symptoms. These symptoms may vary from severe, to fleeting or persistent and can form a vicious circle. If you are tired, you don't feel like exercising and if you don't exercise then often you become tired and lethargic.

It is important to ensure a balance between exercise and rest - exercise and rest intermittently as the body allows. Listen to your body, it will tell you when it is time to rest. Increasing stamina allows you to gain more strength and muscle tone. Remember that rest is also needed to restore energy.

### **What physical activities will I be able to continue with?**

Activities that strengthen your stamina and don't cause stress to the joints and muscles are advised. These include swimming to provide an all over fitness, walking and cycling. Jogging should be avoided as this may prove too strenuous. It is always advisable to ask the advice of your Physiotherapist and/or Occupational Therapist when thinking of starting any exercise regime.

### **What changes will I have to make to my lifestyle?**

Remember you are not alone in making changes, there are people who can help you. Everyone is an individual and will cope with their illness in different ways. Lupus itself can alter the way you will cope emotionally, this may also change from day to day. Talking to other people may be an important way to cope. This may be with family and friends, your hospital consultant, nurse or other health care professionals. However, you may need to talk to someone who has experienced what

you are going through and this is where by joining LUPUS UK and being a part of a Regional Lupus Group may help.

These groups not only offer a chance to talk to other people with the disease but provide you with an up-to-date awareness of changes and developments in lupus treatment and care. Family members and friends also need help and support to enable them to understand the difficulties you are facing. There is always someone who will spend time with you even if you don't want any answers and all you want is someone to listen to your fears and anxieties.

### **What about work?**

As with exercise, the most important thing is to listen to your own body; it will let you know when you need to take a rest. There is no doubt that some adjustment to your lifestyle will have to be made. However, how you learn to cope with these changes will be an important part of the process of adjustment.

Take time to think of the activities you did before you had lupus. Changes may be necessary but these need not be negative ones. Learning to cope with your lupus and taking control of it and not letting it control you will enable you to act with a positive attitude.

It may be that you cannot manage to work the hours you used to work. However, this may not be an option due to financial commitments. There are other ways to overcome this hurdle. You may be able to spread the hours you work over more days or be able to take a break in the day as many continental countries do. It is now more than ever crucial to look after your body. It is no good pushing yourself to the limit. Learn to pamper yourself a little, learn to accept help when offered and don't push yourself to do anything that may be unnecessary - some things can wait until tomorrow.

Remember the body also needs time to rest and rejuvenate and start again.

### **What changes will my family have to make?**

Lupus may initiate the need for changes in your family life; some of these may be permanent, others may be more temporary. There may be some friction between families if, for example, you are no longer able to do all

the chores you used to be able to do. You may have to ask for and accept more help. Your family may be understandably worried about your health and go to the extreme of not letting you do any of the things you used to do. This will lead to you feeling undervalued and make readjusting your lifestyle harder. Try to think of how this change is affecting your family, they also will need time to adjust. Make sure you find time for your family and try to share your fears and anxieties with them. Consider how you would feel if the change was affecting them. Allow time for the things you enjoyed together before you had lupus and continue to enjoy them.

### **What about my sex life?**

There is no doubt that your appearance and behaviour may change with lupus. You may feel more sensitive to these changes and feel that your partner doesn't understand. It goes without saying that some relationships do end but this is a fact of life and happens even without an illness. You need to be able to communicate what you are feeling, what anxieties you or your partner have and if you can't solve these alone perhaps it is time to seek professional help.

Lupus can certainly affect your sex life and the closeness of your relationship. There may be psychological and physical reasons for your sex life to become affected. Physically you may be experiencing muscle and joint pains and not feel able or want to move around. Pain can restrict the activity of love making, therefore, it is important to try and find ways to relax muscles and reduce pain. Massage, warm baths and relaxation may help. You may need to try different positions to put less strain on joints. Learn to talk to your partner about what is comfortable for both of you. Take into consideration the time of day you make love. If you experience early morning loss of mobility you might want to restrict your love making to afternoons or evenings. Fatigue as previously mentioned can affect 90% of people with lupus. Therefore, if you are tired you will not enjoy lovemaking. However, talk to your partner and let them know why you don't want to make love. Being close to someone in their arms can also be a loving experience.

Other problems that may be encountered are: Drugs may be painkillers that make you feel drowsy. As with coping with the pain, find time when you have