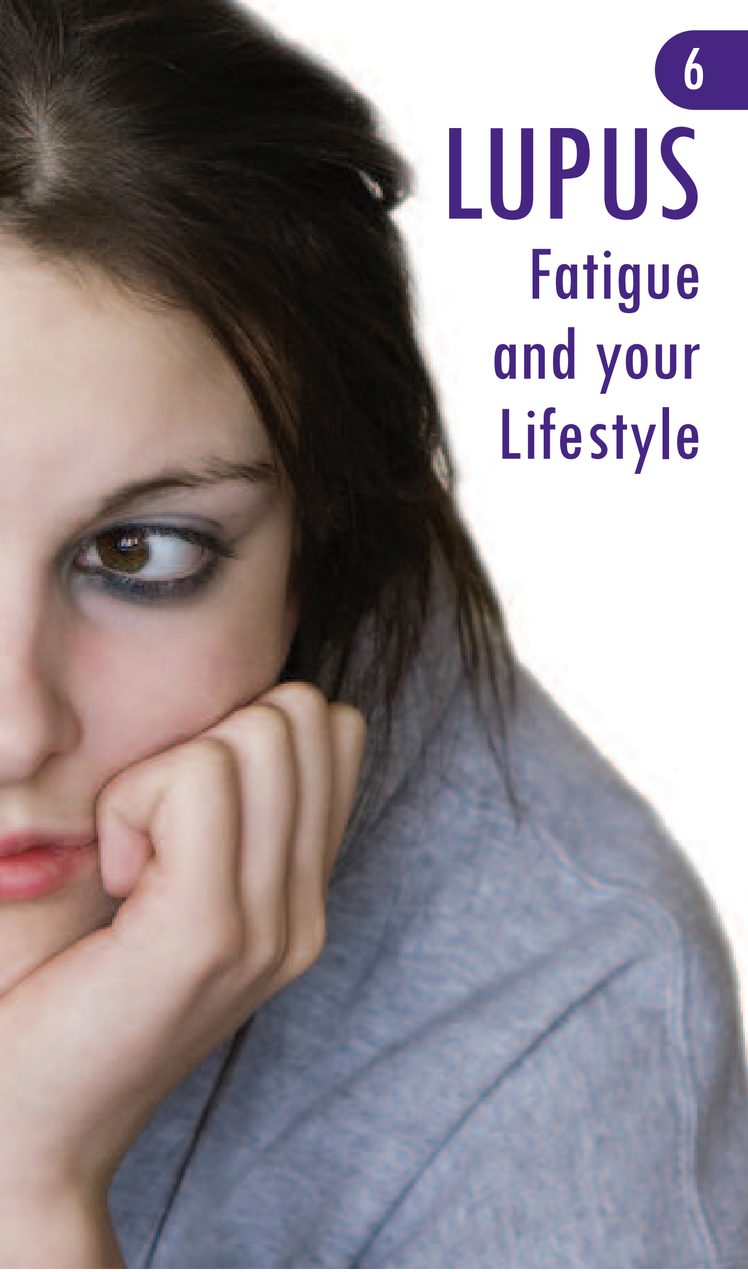
6

LUPUS
Fatigue and your Lifestyle



LUPUS UK

LUPUS

Fatigue and your Lifestyle

This factsheet endeavours to answer some of the many questions regarding 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. As a result, substantial impairments in quality of life and work disability are common.

Unfortunately there are currently no recommended drug treatments for fatigue, however there is some evidence that exercise is beneficial. 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. Some people with lupus also try self-management techniques such as mindfulness meditation and pacing to combat fatigue.

What physical exercises 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 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. If there is no active Regional Group in your area perhaps make use of social media and contact other lupus patients for online support via HealthUnlocked.com/lupusuk

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. Learning to pace yourself is important in being able to reduce stress levels and use energy more efficiently. Further information on pacing strategies can be obtained from National Office.

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 crucial than ever 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.

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 enquiries 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.

For further help LUPUS UK can provide the following booklets: ‘I want to work - A self help guide for people with lupus’ and ‘When an employee has lupus - An employer’s guide’.

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 within 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 may 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.

Be prepared to make changes – learning to live well with a chronic illness and what it means. Identifying different foods and activities that trigger flares can be very helpful in managing your lupus. The LUPUS UK Progress Diary (available from National Office) can be used in this way.

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 the activity. However, talk to your partner and let them know why you don't want to have sex. Being close to someone in their arms can also be a loving experience.

Other problems may be encountered. If you take painkillers which make you feel drowsy, find the time when your pain relief is adequate and you are feeling rested. 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!

If you have Raynauds, the circulation of blood being restricted may also cause you to feel pain and uncomfortable during sex. 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

Friends may respond to your condition in a wide variety of ways depending on their personality and your relationship with them, 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. As previously mentioned, try to pace yourself in order to continue to enjoy your life like many others with lupus do.

Hopefully this factsheet 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 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**
19. **LUPUS Bone Health and Osteporosis**

LUPUS UK is the registered national charity caring for people with lupus and has over 5,000 members who are supported by the Regional Groups.

LUPUS UK acknowledges with gratitude the assistance of Dr Neil Basu, Senior Lecturer (Clinical), The Institute of Medical Sciences, Aberdeen, in the provision of clinical information towards updating this factsheet.

LUPUS UK also thanks the Wooler Walkers (Northumberland) for their valued fundraising 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.

Health & care information you can trust
The Information Standard
Certified Member

LUPUS
UK

St James House, Eastern Road, Romford, Essex RM1 3NH
Tel: 01708 731251   www.lupusuk.org.uk
Reg. Charity nos. 1051610, SC039682

Last reviewed April 2017 - Next review due April 2020

5k RW 5/15