

# My Lupus

## What I Need to Know

A Young Person's Guide

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if requiring further advice on matters reported in this publication.





## My Lupus: What I Need to Know

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## Introduction

This booklet is intended to help you understand more about lupus. You may have wondered why you need blood tests or why you have to take medicines. Understanding these and other issues may help you feel less worried and allow you to take control over your disease.

Your parents may also want to read this booklet so they too will have a better understanding of lupus. However it is important to remember that this is your illness and you are ultimately responsible for looking after your own health.

Friends and family are very important to you. Having lupus may however make you feel less good about yourself at times. You may not know how to handle aspects of your disease and treatment around your friends. The tips and suggestions in this booklet will help you face these daily challenges.

If you have just heard you have lupus, you may find reading all this information overwhelming. You can just read it gradually, when certain questions or issues arise.

Please remember your family, friends and hospital team are the best people to talk to and help support you at any time.



## What is lupus?

Systemic Lupus Erythematosus (SLE) or "lupus" is a disease that causes inflammation in many different parts of the body. Inflammation is a process that causes part of the body to become hot, swollen, or red. It can affect the skin (causing a rash) or the joints (causing arthritis). It can also cause inflammation to organs you cannot see such as kidneys, heart, lungs, and the nervous system. If the inflammation is not treated properly it can sometimes cause permanent damage.

Lupus is called a chronic illness, which means it may go on for many years, perhaps life long. However, effective treatment will mean you can feel well and you may be able, with the guidance of your doctors, to stop your medication.

Living with lupus is often unpredictable. There will be times when your lupus symptoms will be more intense (called a flare). These flares may be associated with certain triggers such as infections or stress. Noticing these connections can help you manage your health more easily. There can be times when your lupus flares for no apparent reason.

## What causes lupus?

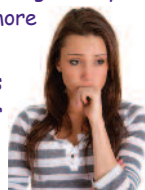
The cause of lupus is unknown. We know that it involves the immune system being over-active. The immune system is there to protect us from foreign invaders such as germs, bacteria or viruses. In someone with lupus, the immune system gets confused and attacks not just the invader but also the body's own tissues. This is called an auto-immune response. The end result is that different areas of the body become inflamed, and can be damaged. It's a bit like if you have a bee sting, the area around it swells up in order to start the healing process and that is why it's painful to touch.

You can't always see the inflammation but it can cause problems within the body, especially when left untreated. It seems likely that there are some genes that may also make someone more likely to develop lupus, although doctors are still doing research to understand this better.

## Why me?

Nothing you did, or did not do, caused you to get lupus. Lupus is not contagious - you didn't catch it from someone, nor can they catch it from you. Lupus is more common in girls and seems to occur more often in some ethnic groups.

There is a tendency to develop lupus in some families, however this is not common. The risk of your brothers and sisters, or, eventually your own children developing lupus is very low.



## What are the signs and symptoms of lupus?

The signs and symptoms of lupus can vary widely from being very mild to more serious. Generally, around the time of diagnosis is when you feel the most ill.

The specific symptoms of lupus can include:

- Fatigue and tiredness - this is a very common problem for people with lupus
- A butterfly-shaped red rash over the cheeks and bridge of the nose (also known as a malar rash).
- Photosensitivity - this is when ultraviolet light, such as normal sunlight, or artificial lights (fluorescent lights or sunbeds) cause a bad lupus rash, or a lupus flare. This can happen on any part of the body which is exposed to ultraviolet light.
- Mouth ulcers - ulcers on the tongue, inside of the mouth or nose, which are usually painless.
- Joint problems - pain, warmth, stiffness and swelling in the joints (arthritis). This type of arthritis does not generally cause long-term joint damage.
- Inflammation of the lining around the heart and lungs (serositis) may cause pain, breathing problems, or fluid to accumulate in these areas.
- Kidney problems - inflammation may cause damage to the kidneys (nephritis) and if untreated may result in kidney failure. This is more commonly seen in children and young people than adults.
- Inflammation in the brain can cause headaches, fatigue, memory loss, mood swings and very occasionally more serious problems such as fits (seizures).

However, you probably will not experience all of these symptoms.

## What happens when I am diagnosed?

A team of people are there to look after you and help you feel better. First of all your doctor needs to be sure you have lupus. Lupus is not always easy to recognise, especially in young people who may not have the characteristic rash. Lupus can begin with fever, tiredness, lack of energy, poor appetite and general aches and pains. It can feel like having a cold or flu that just isn't getting better, or you may feel very ill. Usually the doctor makes the diagnosis after listening to all your symptoms, examining you completely and doing some tests. Blood tests help to confirm the diagnosis of lupus but no one test or symptom can confirm the diagnosis of lupus. You may also need special tests such as scans.

Once the diagnosis has been confirmed the doctors will explain to you how they want to make you better and what medicines you will need.



## What laboratory tests are done in lupus?

Blood tests are important to help diagnose lupus and to monitor its activity.

At each clinic visit, quite a thorough "check-up" is usually undertaken, but this will usually just involve one blood or urine test.

### The laboratory tests can include:

- Anti-nuclear antibody tests (ANA) - the ANA test is positive in almost all patients with lupus. However, it may be positive in many other illnesses, and therefore cannot be used to diagnose lupus on its own. If it is negative, the diagnosis of lupus is far less likely.
- Anti-double-stranded DNA antibodies (dsDNA) - if positive, a diagnosis of lupus is very likely. An increase in dsDNA levels can be a signal of a flare.
- Extractable nuclear antigen antibodies (anti-ENA) - this is a group of tests, some of which can be indicators of lupus which can be linked to certain lupus symptoms.
- Serum Complement (C3 and C4) - a fall below normal levels often indicates a flare, as both C3 and C4 proteins are "used up" in active lupus.
- Erythrocyte Sedimentation Rate (ESR) - this test is raised by inflammation. It is not specific to lupus and can go up when you have various illnesses such as colds or flu.
- Full Blood Count (FBC) - this counts the number of cells in a sample of blood. The white blood cells, red blood cells and/or platelets can go down in lupus.
- Urine Test - this is an important test to check whether the kidneys are affected, as often kidney inflammation will not cause any noticeable symptoms. If the kidneys are inflamed, red blood cells, and/or protein may be found when the lab tests your urine. There is not usually enough blood for your urine to look red. A urine sample will therefore be requested at each clinic visit.





- Other tests may only be carried out routinely every year. These may include levels of cholesterol and other antibodies (e.g. anti-cardiolipin antibodies) which can be abnormal in lupus, but importantly are treatable.

## What other tests will be performed?

Lupus can cause inflammation in different organs in your body and it may be necessary for you to have further medical tests to ensure that these organs are healthy. If you have any symptoms, such tests will be carried out more frequently.

**Some of these tests may include:**

- Lung Function Tests - these tests look at how well your lungs work. You will be asked to blow into a special machine. You may also need special pictures of your lungs to be undertaken, with a chest x-ray or scan. You won't feel any pain or any different when these lung tests are carried out.
- Echocardiogram - this is a test that provides a picture of your heart and looks at how your heart muscle moves and pumps blood around the body. Having an echocardiogram doesn't hurt and will show whether there is any inflammation affecting the heart lining.
- Kidney biopsy - this is only performed if it seems your kidneys may be affected. A biopsy is where a small amount of tissue is taken from the kidney and examined under a microscope. This is usually performed in hospital under a short general anaesthetic (where you are "put to sleep") or sedation (where you are given a medicine which makes you very sleepy and relaxed), depending upon your age.



## How will I get better?

There are medicines to help you get better and keep you well. The treatment is aimed at reducing inflammation in your body and avoiding a flare of your lupus. The treatment you have will change from time to time. This will depend on how lupus is affecting your body. It is very important that you take your prescribed medication regularly. Sometimes you may not need any medicines.

There are lots of medications which can help in lupus. Your doctor and nurse will explain which ones can help you. They will explain the drugs to you and give you much more detailed written information to take away.

**Here are some of the drugs that may be used:**

**Prednisolone** - this is the most effective drug for controlling lupus initially. It is a steroid but is not the same kind of steroid drug that some body builders take. This drug works to decrease the inflammation caused by your lupus. Taking prednisolone is a bit like pouring water on a hot fire to put it out. It is very good at putting the fire out and "dampening down" inflammation in the body but when you stop putting water on it, there is a risk the fire may come back and "flare-up" again. Steroids are therefore usually used with the other medicines discussed below, to reduce the on-going need for more and more steroids.

This is important because steroids can have side effects, which relate to the dose you take, and how long you take them for. When you are diagnosed you will probably have to take higher doses of prednisolone. As your lupus improves your dose will be lowered gradually and any side effects you've had will reduce. Some side effects you may notice are:

- Increase in appetite
- Increase in weight
- Puffy face
- Acne
- Mood swings
- Stretch marks
- Slower growth
- Increased body hair

In the long term you may develop side effects that you can't see such as:

- Weaker bones
- High blood pressure
- Increased risk of infection
- Cataracts - this is a cloudy area, which develops in the front of the eye. This type of cataract is different to the cataracts older people get, and they usually do not affect vision.

After reading about these side effects, you may feel anxious about prednisolone. However, it is the best drug initially for treating your lupus. Doctors would not prescribe it if they could treat your illness in another way. They will always use the lowest dose possible to get you better. Side effects will go away as your dose is lowered, but it is important to wait until your doctor suggests reducing your dose.

Prednisolone is similar to chemicals naturally produced by your body. Treatment with prednisolone fools the body into shutting off its own steroid production. These chemicals are vital to regulate normal daily body function. Therefore, never stop your prednisolone abruptly or you may become extremely sick. Stopping your prednisolone quickly is also likely to cause a lupus flare. Your doctor will reduce your prednisolone gradually guided by your symptoms and blood test results.



**Methyl Prednisolone** - This drug is similar to prednisolone except it is given into a vein in your arm. It is often given in the early stages of your lupus when it is quite active or may be given later if your lupus flares-up.

**Hydroxychloroquine** - This is a drug that most patients with lupus will be on for many years, alongside other treatments. It has been used for treating lupus patients since the 1960s. It helps treat the rash in lupus and prevent flares when the prednisolone dose is being reduced. It has relatively few side effects. It is possible that



hydroxychloroquine may affect your eyes, however at the dosages that most clinics use, this has not been demonstrated to be a problem. Your doctor will therefore refer you to have your eyes checked every few years by an eye specialist (ophthalmologist). In mild lupus (e.g. skin involvement only) you may only be on hydroxychloroquine.

**Azathioprine** - This drug helps reduce inflammation in major organs such as the kidney. It may also reduce the need for high doses of prednisolone. It works by suppressing the immune system and therefore you need to have regular blood checks.

**Mycophenolate Mofetil (MMF)** - This drug can also be used to treat inflammation in major organs (e.g. kidney, blood, brain), similar to azathioprine.

**Methotrexate** - This drug reduces inflammation by acting directly on the immune system. It can affect both the white blood cells, which fight infection, and also the liver enzymes, so regular blood tests are needed. Methotrexate is most commonly used for arthritis and skin involvement.

**Cyclophosphamide** - This is a powerful immunosuppressive drug that helps to rapidly decrease the activity of the immune cells causing inflammation. Cyclophosphamide may be given once a month, as part of a course of treatment, through a drip into a vein, and may require a brief overnight stay in hospital.

**Rituximab** - This is an immunosuppressant drug used in severe disease and only when you have tried other drugs. It is given in hospital through a drip into a vein in your arm. Two doses of rituximab are given two weeks apart. They may or may not need to be repeated.

**Belimumab** - This is not currently available for use in children although clinical trials are ongoing. For further information about this treatment in adults, refer to our factsheet LUPUS and Medication.

**Steroid drug card** - you will be given a card to carry with you telling doctors you are on steroids and other medicines, which affect your immune system. In the event of an accident, medical staff need to know which medicines you are taking.

## What happens when I come to clinic?

Clinic visits are essential to enable the doctors and team to monitor your disease activity and to adjust your medication and any other treatments. It is very important that you attend your clinic appointments even if you are feeling well. You will be seen by your doctor at every visit and by different members of the rheumatology team when



necessary. This could be the nurse specialist, the occupational therapist, physio-therapist or psychologist. The doctor may feel that you need to also be seen by a different type of hospital specialist (e.g. nephrologist for kidney disease or neurologist for brain symptoms). You will be examined at each visit and have your blood pressure checked. You will be asked to give a urine specimen for testing and usually have a blood test. As you get older you will be asked if you want to be seen on your own for all or part of the clinic visit. Many young people value this opportunity and it is good practice for when you are older and attending adult clinics.

## Transition from Paediatric to Adult Services.

### What is transition?

In a hospital, transition is the process of moving a young person's care from the paediatric (child) service to the adult service and thinking about ways to help them with this. Becoming a young adult can be an exciting time with many changes and opportunities such as

- Going to a new school or college
- Going to university
- Getting a job
- Making new friends



As you become a young adult, the children's hospital may no longer be the best place for you to have your treatment. As you are growing up you may feel ready to move on to a more adult setting.

Some people feel very ready for this, for others, it can be hard to leave behind the things they are familiar with and to move on to new places and challenges.

### When will I transition?

The point at which care moves to an adult service will be different for each person depending on a number of factors including

- Your current treatment
- How well you are at present (whether you are in the middle of a flare)
- Your life plans (are you moving away to go to university)
- The specifics of your local paediatric and adult services

It will be important for you to discuss the best time for you to transition with your medical team. For lots of people it is around the time they are 18. It is likely that your medical team will start to talk to you about transitioning when you are much younger than this so that you can work together to identify where you will transition to and what support you might need to ensure this happens smoothly.

### What might Adult Services be like?

Adult services can be quite different to paediatric settings and it is important that you know how to find out more about what the adult service you will use will be like.

Some have dedicated adolescent/young adult clinics that are designed to support young people moving up from children's services. The clinic slots might be a bit longer and they will be used to supporting people who are new to adult services.

## Who can help me?

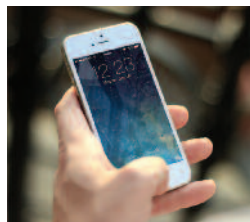
LUPUS UK has trained volunteers, called Contacts, who either have lupus themselves or have a family member with the condition. You can speak to them on the telephone and they will listen to you and give emotional and general help or signpost you to someone who can advise you. This telephone service is given freely and is completely confidential. You can set the time of the call and disclose as much as you wish. Telephone LUPUS UK on 01708 731251 (9am - 5pm Mon-Fri) and we will give you the name and telephone number of one of our Contacts.



## What can I do to prepare to move to adult services?

There are a few things that you can do to start to get ready for moving to adult services.....

- Learn more about your condition and treatment so you can be involved in making decisions about your care
- Start to take more responsibility for taking your medication/requesting prescriptions
- Keep important phone numbers in relation to your lupus care in your diary, mobile phone or calendar
- Start to take responsibility for remembering your appointments (put the dates in your phone, diary etc)
- Practise asking questions yourself when you go to clinic (perhaps write them or jot them in your phone before you come)
- Try spending a few minutes talking to your doctor in clinic without your parent or carer in the room
- Find out who to contact if you require help urgently or in an emergency in relation to your lupus
- Let the paediatric team know what help you might need to feel ready to move to adult services
- Let the paediatric team know when you feel ready to make the transition



## Is there something I can do to help my lupus?

There are things that you can do to help yourself in addition to taking medications:

**Sun protection** - sun protection is important because sunlight can make your lupus worse or trigger a flare.

- Use a sunscreen lotion or roll-on with a sun protection factor (SPF) of 50.



- Be sure to apply 30 minutes before going out, even on cloudy days, and in the winter, and don't forget to use it on your ears. Find the preparation which best suits you (some rub in better than others).
- Protect exposed areas with a hat and long sleeved shirts.
- The sun is strongest between 10am and 2pm and you should avoid exposure at this time.



Sometimes lupus may be affected by artificial lighting such as fluorescent, halogen and LED lights, so do check whether the lighting in your home or school could be affecting you and could be filtered or the bulb strength reduced.

**Fatigue and pacing** - fatigue is very common in lupus. You may have a limited pot of energy, so it is important to pace yourself and not overdo it. It's all about prioritising and taking things at a steady pace, so you get done what you need and want to do. Don't participate in activities until you get completely exhausted. Ask for help when you need it. Listen to your body and if you feel tired, rest even if it's only for a few minutes and then resume your activity. You may find that resting for 30 minutes when you get home from school will help to give you energy to do activities in the evening. Your medical team can give you a lot of helpful advice.



**Exercise** - exercise is always important but during a flare of lupus you may want to reduce your sports activity. Once you are feeling better it is important to get back to doing some physical activity. Exercise helps strengthen your muscles and bones, keep joints flexible and controls weight.

**Diet** - no special diet will cure or prevent a flare-up of your lupus. A well- balanced diet that includes a variety of foods, especially fruit and vegetables, is key to healthy nutrition. Try to avoid eating too many foods which contain high levels of sugars, salt and fats. Plan to eat foods high in calcium (e.g. milk, cheese, cauliflower, broccoli) to help keep bones strong. If it is difficult to receive enough calcium through diet alone, your doctor may prescribe a calcium supplement.



Remember that prednisolone can cause you to feel hungry and this increase in appetite is not your fault. If you try to replace crisps and sweets with fruit, vegetables, nuts and seeds this may help to slow down any weight gain.



**Are there any vaccinations or immunisations that I should or shouldn't have?**

These are very important. Always check with your nurse specialist or doctor if you are unsure, especially if you are on medicines which suppress your immune system (e.g. prednisolone, azathioprine, MMF etc).

There are two vaccines that your doctor may recommend you have because of your lupus. These are injections, which can be given by your family doctor:

- Flu vaccine - it is wise to get vaccinated every year in October or November. The injection is an inactive 'dead' form of the flu virus, so it cannot cause an infection. The nasal spray vaccination is an attenuated 'weakened' form of the flu virus which could potentially pose a risk of infection in those with a compromised immune system.
- Pneumococcal vaccine - this vaccination is recommended for all patients with lupus to protect against a serious infection in your blood or lung.

## April's story

*Hi my name is April, I am 14 years old and I was diagnosed with lupus in May 2014. I am not going to lie, lupus is hard, but you just need to get used to it. At first it horrified me reading all the stories and hearing what different people went through having lupus.*

*I am a teenager with an illness and it is hard, no one really knows or can even imagine how you feel or what you are going through. It stops me sometimes doing all the things that my friends do. I want to prove to myself that I can go all day and do things all night just like all my friends but deep down I know that I can't just yet, I have to rest and my mum has taught me that.*

*Friends and family are so important, without them it is so hard. You need them to help you or make you laugh when you feel at your worst. My mum helped me the most when I was so bad that I could not even walk on my own, and held herself together even though it was hurting her just as much as me. I am still not at my best but I know that I can only get better and I hope that I am going to be off all my tablets and be back to me, April, maybe not this year and maybe not next year but sometime in the future.*

*If you have just been diagnosed with lupus try not to get yourself into the state I did, you can only get better; just trust in your medication and you will be back to yourself!!*

## When should I see a doctor?

You will get ordinary colds just like anybody else. However, infections can potentially be more serious in young people with lupus. If you develop a high fever (greater than 100oF or 38.5oC) or feel increasingly unwell, always get in touch with a doctor quickly. Always contact your doctor if you are worried about your lupus.

## Will I have to see other doctors?

Over the course of your illness you may have to see a variety of doctors or specialists at the hospital. You may see the nephrologist if you have kidney involvement or the dermatologist if you have skin involvement such as a rash or acne.

## Managing your lupus

The most important thing is taking your medication and attending clinic for regular check-ups and blood tests. If you have some of the side effects of prednisolone,



particularly weight gain, continuing to take your medications can be more difficult. Many young people sometimes lose interest or get fed up following their treatment plan. Remember to discuss your frustrations and worries with your family, your doctor, nurse, or another member of the team who you feel comfortable speaking to.

## Knowing about lupus

Knowing as much as possible about lupus will enable you to make sensible and informed decisions. Recognising your own symptoms and knowing small changes may affect your body will help you manage your disease. Being able to follow your own treatment plan can help you feel in charge and also help you to become familiar with how lupus affects your body.

Beware of parts of the internet and scare stories you may hear about lupus. Always ask your medical team about how lupus affects YOU. Different lupus patients can be affected by their disease in very different ways. There are some very helpful and informative websites provided at the end of this booklet.

## Why do I feel angry and sad sometimes?

Feeling angry and sad are normal emotions when dealing with a long-term illness like lupus. You may feel like you are on an emotional roller coaster. At times you feel in control and can handle it well, while other days you feel frustrated and afraid. Remember, it's normal to have many different feelings. Below are some hints, which may help you in dealing with some of these thoughts.



Know about your lupus and know what to expect. Lupus has its ups and downs, one minute you feel great, the next you may feel rotten. This is a natural part of lupus and what many other patients experience.

Talk to someone. Talking may help you feel better and help you learn other ways to handle problems. Keeping your feelings bottled up inside can make you feel worse. Talking to friends and family helps them know how you feel and allows them to try and help you. It may be helpful to talk to someone who is specially trained to assist with the social (friends, school), emotional (feelings) and practical (financial) problems brought on by your lupus such as a social worker or psychologist.

It may be helpful to think in advance about things that could leave you vulnerable to a flare such a stress from exams, changing schools, starting a job. You can then work together with your family/friends/school to work out a plan to manage in advance, rather than trying to pick up the pieces after a difficult time. Developing resilience (the ability to bounce back after a tricky time) is important. It is about developing coping strategies that you can use in all areas of your life, not just in relation to your health. Knowing what helps to lift your mood (as well as what brings it down), knowing who you can turn to for help and when to do so, as well as managing your time are all important skills to develop.

- You may find it helpful to contact other patients with lupus to share experiences or learn from each other - you can contact LUPUS UK, which is a charity that supports people with lupus (01708 731251) or ask a member of your medical team. All of these calls will be treated in confidence.
- Talk to your doctor, nurse or other members of the medical team in confidence. Knowing your medical team knows how you feel and that you're not alone can be helpful. It may be possible for them to arrange for you to see a psychologist or meet other patients with lupus.
- Continue to be involved in the activities you enjoy, but also look for other interests, which may use less energy. You shouldn't have to give up sports or other activities in or outside of school, although occasionally you may not be well enough to take part. It is important to change as little as possible in your normal routine. Feeling good about yourself can help lessen negative emotions you may feel. Here are some ideas on how to look and feel better:

- Cover skin rash with makeup/foundation - there are specialist services that can help you (see Changing Faces in the contact listings at the end).
- Use special cleansers and soaps to help your acne. If these don't work speak to your doctor who can prescribe a stronger cream.



- If your hair is thinning use a mild shampoo, try not to wash your hair every day, and don't use rubber bands or clips that may pull your hair. Avoid colouring your hair and using heated appliances (e.g. hair straighteners) too often.
- If your face looks a little rounder due to prednisolone try a hairstyle that pulls attention from the cheek and jaw area. You can get advice on styles, which would suit you from most hairdressers.
- Recognise your strengths and be proud of yourself - living with a long-term condition is not easy. Make a list of all the positive things you can think about yourself. Ask others to help you.
- Have a "cheer up" box to help lift your spirits - with your favourite music, dvd, photos, etc - things which you enjoy and mean a lot to you.



## Jake's story

*When Jake was 6 weeks old his mum put him on the balcony of their Liverpool flat to get some fresh air. She looked at him five minutes later and noticed that his nose had got quite badly sunburnt. She thought she was a bad mother for having let this happen.*

*He regularly caught lots of colds and other illnesses, but even so he was always happy. They would visit the GP, who usually said, "He's got a virus". His Mum, Debora said "I knew something was really wrong with Jake when he was five, as he was quite poorly, lost a lot of weight, and the rash across the nose kept coming back. So I asked for him to be seen at the hospital".*

*Whilst waiting for the hospital blood tests to come through she went to the library and looked up "rash on the nose" on the internet. The response was instant: butterfly*



rash and lupus. When they saw the hospital consultant she immediately asked if Jake had lupus, the doctor was astounded and asked how she knew. "I felt so angry that the doctors hadn't known what it was when I'd done a simple search on the internet and found out".

Jake had to miss a lot of school for a couple of years following his diagnosis at six, but now at 13 he is back at the right level and doing well with his studies. His motto is "work hard, play hard". 'He's got a cracking set of very loyal friends - they understand about his illness and are there for him, but if one of them isn't well they stay away from him as they know how easily he picks up infection and that can make him really ill", says Debora.

Jake would rather not have lupus, but he doesn't complain about anything: "I've been through so much it's made me strong. Don't let it beat you or get you down. Stay strong. I keep out of the sun and always slap sunscreen on every day as the sun is out there, whether you see it or not".

His advice to others is "It's good to have a lot of friends because they make you feel better. You've got to get on with life. Don't forget to take your medicines and ask people to keep away when they've got colds, so that they don't pass it on to you. There are people out there who understand this illness. Give yourself an activity to get involved in, like football or basketball".

## Pain

Pain doesn't affect a lot of young people with lupus, but for some, it can be a problem, especially in the early days after diagnosis.

It is often difficult to explain pain to other people, especially when you are tired and feel unwell, so it may be better if you talk to your family and care team when you are not in the middle of a painful episode.



Sometimes you may not know exactly where the pain is, or how to describe it, as it may feel like a cloud all around you. It may be really difficult to know what is causing the pain and not all pain can be explained by doctors. Keep notes on when you experience pain to see if there is a pattern - sometimes you will be able to tie it to activities you did yesterday which could have caused it. You may have just done too much or sat in the same position for too long: you might be in a really noisy environment which causes a headache and makes you feel extra tired.

**Your doctor and care team will really want to help if you feel pain.** They may give you pain relief medication which can help. However, the whole team of people caring for you can help by teaching you ways to help cope with any pain.

Sometimes warmth or cold may help: you can use a warm hot water bottle (or fill it with icy water if you want it cold) or use special wheat bags which can either be warmed up in the microwave or put in a plastic bag in the freezer. Make sure that the bottle or bag has a cover on it, or wrap it in a towel or piece of cloth. Never put it directly next to your skin as the temperature can damage the skin: only use it for 10-15 minutes at a time and repeat if necessary after a 15 minute break.

## What should I tell my friends?

What you choose to tell your friends about lupus is up to you. You may only want to tell your very close friends. Others may choose not to tell anyone about their disease. Remember if no one knows about your disease it is hard for them to be able to help.

It can be good to think about how much information you feel comfortable sharing and with whom.

For example, it can be good to practice how you might want to answer questions about your lupus so that you feel comfortable with what you want to say. You might want to practice the answer you might give to someone you know well, versus a shorter answer that you might give to someone you don't know very well. Often giving a simple explanation is all that is needed. After you have said what you want to about lupus it can be good to change the subject so that you don't get caught up in a lengthy discussion about your illness when you don't want to.



## Some ideas of what you might say are:

"I have lupus, which is an illness that causes a skin rash, joint pain and makes me get very tired sometimes. What did you think of last night's episode of xxxx?"

"Thanks for being interested. I have an illness that means I have to take medicines and go into hospital sometimes. Do you have any nice plans for the weekend?"

If you need to take large doses of prednisolone for a period of time and you gain weight some people at school may ask you questions about that. An explanation like "I have to take a medicine which will help me get better, but it makes me put on weight while I'm on it", will help them to understand.

## School/college

It is important that your school or college are aware you have lupus. They may not have had a pupil with lupus before, so don't be surprised if you know more about it than them. Your teacher may find this booklet helpful, or LUPUS UK can provide them with information. It may be that a member



of the lupus team (e.g. nurse specialist, psychologist) can liaise with your school to ensure they understand how lupus affects you. They can help your school to identify steps they can take to support you to do your work and get around school more easily e.g. access to a lift pass, access to a quiet room should you need a rest etc. The 'health passport' form at the end of this leaflet can be useful in helping you to think about how lupus affects you and what support you might need from school. It may be that the nurse specialist/psychologist can help you to complete the form and share it with a key staff member at school such as your head of year or form tutor.

## Will I have to miss a lot of school/college?

Unfortunately, most clinics are in school time but your doctor will try to make your appointment time as convenient as possible. When you are first diagnosed, you will be coming to the clinic fairly frequently but as you get better the frequency will reduce.

Absence from school/college may be a problem early on in your lupus. You may need to go back part time at first but it will not take long before you feel well enough to attend school full time. You may feel unable to take part in physical education on a regular basis. This too is temporary and we encourage you to get back to sports and activities as soon as you feel able.

## Help from school/college

Schools can help a lot with making it easier for you to join in normally, so chat to them about your concerns.

When you are not well this may mean focusing on core subjects, a reduced workload, time to catch up or rest, and extra time to get to classes. You may need to go back to school gradually and not do everything all at once. Do talk to your medical team and teachers if any of these areas are difficult for you - they are very important. With your permission your nurse or doctor can write to your school/college and provide written information about lupus.

Lots and lots of young people with lupus have gone on from school to university / college and have very successful jobs.



## Alcohol, smoking, drugs and sexual health

Alcohol makes your liver more sensitive to the effect of some medicines you may be taking and ideally you should not drink alcohol while taking them. If you are old enough, an occasional alcoholic drink is not harmful. Excessive regular alcohol and binge drinking should be avoided. And REMEMBER - 1 unit of alcohol is equivalent to a half pint of normal strength lager (approx 3.5%), or a small glass of wine. Most Alcos are 1.7 units per bottle! For more information please check out:

[www.talktofrank.co.uk](http://www.talktofrank.co.uk) and

[www.nhs.uk/Livewell/Sexandyoungpeople/Pages/Sexandalcohol.aspx](http://www.nhs.uk/Livewell/Sexandyoungpeople/Pages/Sexandalcohol.aspx)



### Smoking

As lupus can affect the blood vessels, it is even more important for young people with lupus not to smoke as tobacco also damages blood vessels - as well as staining your teeth, giving you bad

breath, dry skin and making you short of breath! To find out more about smoking and/or help in stopping, talk to your GP or one of the hospital team or check out

[www.nhs.uk/livewell/smoking/pages/teensmokersquit.aspx](http://www.nhs.uk/livewell/smoking/pages/teensmokersquit.aspx)

## Drugs

Whether you are thinking about using drugs yourself or know someone else who is using them - it's a good idea to know the facts. Some drugs are more dangerous than others, are highly addictive and can cause serious health problems. You can also die from an overdose or the effects of drugs. Drugs are also illegal.

If you want to know more about drugs and their effects, or if you are worried about a friend or relative who may be using drugs, visit [www.talktofrank.co.uk](http://www.talktofrank.co.uk); or ask one of the people looking after you for more information.

## Sexual health

When any young person is considering becoming sexually active (male or female), it is important to know how to keep yourself and others safe. If you are having sex, it is important always to use a condom. As well as helping to prevent pregnancy, these can protect you and your partner against sexually transmitted infections including: Chlamydia, HIV, syphilis and gonorrhoea.

Some of the drugs used to treat lupus can possibly affect an unborn baby. It is therefore important for sexually active young people to use effective contraception (male and females) whilst taking some of these medicines and for up to 6 months after it has been stopped. Your lupus and /or medication can affect the choice of contraception suitable for you so you should discuss this with your doctor.



Your medical team are always willing to listen to any concerns you have relating to your sexual health, and give helpful advice. Don't be afraid to ask.

For further information about sexual health and young people check out [www.brook.org.uk](http://www.brook.org.uk).

## Pregnancy

You may be wondering about whether you will be able to have children. It's important to plan ahead for getting pregnant so discuss this with your medical team. This can be done in complete confidence. Some women who have lupus experience a flare during pregnancy and others have medications that need to be changed. Lupus may also increase the risk of miscarriage. However, close monitoring by your doctor and an obstetrician will normally lead to a successful outcome and a healthy baby.

All of the people looking after you will be happy to discuss any of these topics with you if you would like. They will also discuss them with you at some point as part of your routine care. See our Lupus and Pregnancy factsheet for more information.

## Natalie's story

*Natalie had a sore throat and didn't feel well just before Christmas 2015, she thought it was because she'd been packing too much into her life, but when she began to have difficulty breathing and a rash all over, it seemed more serious.*

*Doctors put her on antibiotics, but over the next three months her symptoms didn't clear up and she kept having to go to see her GP and A & E at the hospital. She lost*

a lot of weight and was so tired she could barely get off the couch. "I'd never had anything wrong with me and suddenly I was going backwards and forwards to the hospital and no-one seemed to know what was wrong. My mum and dad were really worried as I was always sick and bad".

Four months later, the hospital doctors wondered if she had juvenile arthritis or juvenile lupus, so they kept Natalie in for two months for a lot of tests and treatment, which showed that she had juvenile lupus. Natalie was put onto steroids and other powerful drugs, which brought the lupus under control. Fortunately Natalie has some really good friends who came to visit her to cheer her up during the time she couldn't go out. She was off school for six months, but she had a home tutor who helped her with maths and English.



"The worst thing was that the steroids made my face really bloated, which upset me, but I've been able to come off taking those now, and the other medication I have to take isn't so bad".

Now Natalie is at 6th form college and her ambition is to be a children's nurse. "You take your health for granted until something goes wrong. I know what it's like to be in hospital - I missed seeing my little sister who could only get in a couple of times a week, so I know how important a job the nurses do". Natalie's parents have been great in helping her and she's learned to be positive about life because they always are.

## What's in the future for me?

When first diagnosed with lupus you may feel your life is all upside down and you have little control over it. There are major changes to make such as frequent clinic visits, medications and learning all about a disease you probably had never heard of.



Although these adjustments can be difficult, they will lessen as you become more familiar with living with lupus. As you start to feel better your daily routines of school and social events with friends become a priority and lupus is not always on your mind.



Your career goals, relationships and having your own family are all realistic and important goals to look forward to. If you decide to travel for an extended period of time this may take more planning. However, if you are careful and take precautions there is no reason why any of your future plans should have to change.

There is no doubt that lupus may complicate your life at times. Hopefully this booklet has answered some of your questions about lupus. Having a good understanding of lupus will enable you to take responsibility for yourself and your treatment programme.

## LIST OF USEFUL WEBSITES AND CONTACT NUMBERS

LUPUS UK: [www.lupusuk.org.uk](http://www.lupusuk.org.uk) tel: 01708 731251

Arthritis Research UK: [www.arthritisresearchuk.org](http://www.arthritisresearchuk.org) tel: 0300 790 0400

Alcohol: [www.nhs.uk/livewell/alcohol](http://www.nhs.uk/livewell/alcohol)

Drugs: [www.talktofrank.com](http://www.talktofrank.com) tel: 0300 123 6600

Smoking: [www.nhs.uk/livewell/smoking/pages/teensmokersquit.aspx](http://www.nhs.uk/livewell/smoking/pages/teensmokersquit.aspx)

Healthy diets: [www.nhs.uk/change4life-beta](http://www.nhs.uk/change4life-beta)

Changing Faces (e.g. cosmetic camouflage): [www.changingfaces.org.uk](http://www.changingfaces.org.uk)  
tel: 0300 012 0275

Medic alert jewellery: [www.medicalert.org.uk](http://www.medicalert.org.uk) tel: 01908 951045

Financial Help if you are disabled: [www.gov.uk/financial-help-disabled](http://www.gov.uk/financial-help-disabled)

## INFORMATION ON LUPUS RESEARCH FOR YOUNG PEOPLE

- LUPUS UK: [www.lupusuk.org.uk/lupus-in-young-people/](http://www.lupusuk.org.uk/lupus-in-young-people/)
- UK JSLE Study Group website:  
[www.liverpool.ac.uk/translational-medicine/research/ukjsle/about/](http://www.liverpool.ac.uk/translational-medicine/research/ukjsle/about/)
- Experimental Arthritis Treatment Centre for Children (EATC)  
[www.liverpool.ac.uk/translational-medicine/research/eatc/facilities/](http://www.liverpool.ac.uk/translational-medicine/research/eatc/facilities/)
- GenerationR (young people improving Research): [www.generationr.org.uk](http://www.generationr.org.uk)
- Centre for Adolescent Rheumatology:  
[www.centre-for-adolescent-rheumatology.org](http://www.centre-for-adolescent-rheumatology.org)

# Lupus Specific Health Passport/Care Plan

Completed by	Young Person:	
	Health Professional:	
Date Completed:		
Review Date (if no changes required prior to this):		

## What is the Lupus Health Passport?

Long term health conditions can have an impact on a young person in every aspect of their life. This document has been put together to help you talk to your school/college or university about how lupus affects you, how it might have an impact on your education and what can be done to help you manage.

It may be helpful to complete this together with a doctor, nurse or other health professional who knows you well. Have a think about what information your school/teachers might need to know in order to best support you.



# Information to help my teachers understand more about lupus and how it affects me

## What is lupus?

What is lupus or JSLE (Juvenile Onset Systemic Lupus Erythematosus). Lupus is a chronic autoimmune disease that can affect any part of the body including skin, joints and any of the major organs.

JSLE can be very variable in how it manifests, with some children having a mild disease and others having a very severe disease. The course of JSLE is characterised by episodes of disease flares followed (if treated promptly and appropriately) by periods of improvement.

## Common symptoms of lupus

Children with lupus may suffer with myalgia (muscle pain), arthralgia (joint pain) or arthritis (joint inflammation), and inflammation of the kidneys, lungs and brain. Severe unremitting fatigue (tiredness) is a very frequent and often disabling symptom. Skin rashes, headaches/migraines, depression, light sensitivity, difficulty with memory/concentration and circulation problems are also common experiences.

How does lupus affect me?

Lupus affects me in the following ways:

- .....
- .....
- .....
- .....

Symptoms I often get are

- .....
- .....
- .....
- .....

On good days I can

.....  
.....

On bad days I struggle to

.....  
.....

## My Details

Young Person's Name:		Address:
Contact telephone number(s):	Home:	
	Mobile:	
Parent/Carer Name(s):		Address:
Contact telephone number(s) (parent):	Home:	
	Mobile:	
GP Name:		Address:
Lead Hospital Consultant Name:		Address:
Other practitioners involved in young person's medical care:		
Contact in case of medical emergency:		Phone number:

Medical Diagnoses	Date Diagnosed

Medical Appointments			
Date	Time	Name of Hospital/Clinic location	Clinician/Clinic Visiting

**Main medications** (please list medications and state any particular advice e.g. time of day, if can be self-administered. The school needs to be aware of all medications being used during school):

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.....

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.....

**Treatments and special care options (please complete the relevant fields as applicable):**

- Physiotherapy -
- Occupational therapy -
- Psychology -
- Other -

**My day to day care (consider the following and complete where relevant):**

- How I will pace myself
- Triggers to be aware of: e.g. strong sunlight/artificial light
- Keeping warm, especially hands
- Avoiding people with infections
- Exercise suggestions (home/school PE sessions):
- Other

**Advice on support to be arranged by school/college/uni (consider the following - educational, practical, social, emotional, and complete where relevant)**

- Use of lift at school/college when stairs are difficult to climb
- Assistance in carrying school bag would be helpful
- Assistance in practical classes (where necessary e.g. lab work)
- Consideration of getting from one site to another
- Additional time during exams/project work
- Other educational support necessary
- Designated guidance teacher/support worker to consult regarding social or emotional difficulties
- Who to contact if feeling unwell at school
- Details of school nurse/disabilities officer
- Other

This care plan will be reviewed by both of us on.....

LUPUS UK offers a comprehensive range of books and factsheets on lupus, and can supply free of charge separate Information Packs for individuals, nurses and GPs. The national magazine 'LUPUS UK News & Views' is published on subscription three times yearly and carries regular articles on lupus.

With over 5,000 members, supported by the Regional Groups, we are in a strong position to provide information to the general public and to support those with systemic and discoid lupus and assist those approaching diagnosis.

Please send for our booklet and/or pack and details of membership - we would be delighted to have your support.



LUPUS UK, St James House, Eastern Road, Romford, Essex RM1 3NH  
Tel: 01708 731251

[www.lupusuk.org.uk](http://www.lupusuk.org.uk)

Reg. Charity nos. 1051610, SC039682

The UK JSLE Study Group is a multi-disciplinary collaborative group investigating the clinical characteristics and immunopathology of lupus in children.



## Your Notes

Ruled lines for taking notes.

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



Please contact 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.

Publicity materials, leaflets, posters, a dvd for the newly diagnosed, media releases and more are always available from the charity's National Office for better awareness about lupus in clinics, hospitals and public places.